

South Asian women's Access to Healthcare in Edinburgh

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Abstract

This thesis presents the findings of a qualitative study of access to healthcare among South Asian women living in Edinburgh.

My study aims to provide a detailed understanding of access to healthcare which is sensitive to the perspectives and experiences of South Asian women. Where previous attempts to explain access to healthcare have centred on quantifiable measures of health service uptake and physical distance to caring services, I argue that 'access' and healthcare are in fact much broader concepts than much of the literature implies. To examine these broader notions it is necessary to reconsider how we measure access and define healthcare. In order to explore this my study focuses on three different healthcare arenas. These are 'everyday' healthcare outside health services, the General Practitioner service, and cervical cytology screening (i.e. informal care, general mainstream health servicing and targeted preventative screening services). My findings with respect to each healthcare arena contribute to wider debates on minority ethnic groups' access to healthcare.

The thesis opens with a review of some key literature on minority ethnic groups and healthcare and identifies gaps in research, policy and theoretical analysis. I make particular reference to debates about culture, and 'race' and gender difference in the literature on minority ethnic groups and healthcare. I identify three key problems. Firstly, I challenge studies that focus on the attributes of healthcare users or on measures of health and disease rather than on the attributes of health services and the perspectives and experiences of those who use healthcare. Secondly, I criticise the stereotypical notions of minority ethnic culture which are often used to explain patterns of access, to shape public policy, and to drive research. Thirdly, I criticise a literature on minority ethnic groups and healthcare which is generally gender blind and a literature on women's healthcare which is generally 'race' blind. I argue that these three tendencies contribute to the invisibility of minority ethnic women in debates on health and health service inequalities. This thesis attempts to challenge these problems.

The main body of the thesis draws on findings from 36 qualitative semi-structured interviews with women from the four main South Asian ethnic categories present in Edinburgh (Pakistani, Bangladeshi, Indian (of Hindu heritage) and Sikh). I use women's perceptions and experiences of healthcare in the three healthcare arenas to assess enablements and constraints on access, to explore women's pathways into and around healthcare and to illustrate how and why they use healthcare in particular ways. The research findings are examined in the light of a wider literature on minority ethnic groups and health, and on women's health. My findings challenge conventional understandings of South Asian women's healthcare practices and their patterns of service use.

My study shows that user perspectives are important in understanding access to healthcare. User perspectives allow me to show that access is linked to the life experiences of South Asian women and has many dimensions. Access is affected not only by the uptake of, or physical distance to, services but is affected by social position. My findings show that ideas about 'race' and gender difference affect South Asian women's access and attitudes to, as well as their experience and patterns of, healthcare. I also argue that access to healthcare is affected not so much by the attributes of individual women as by the attributes of health services, and that health services and providers play a role in reflecting and reproducing ideas about 'race' and gender difference. I conclude by emphasising the need for health policy makers and providers to understand and learn from the attitudes and experiences of South Asian women. They need to challenge the structural constraints on access if they are to alleviate South Asian women's access problems and deliver ethnically sensitive services.

Declaration

I, Sheila Paul hereby declare that the work contained herein is my own and has not previously been presented for examination

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List of Abbreviations

AMBC = Asian Mother and Baby Campaign

CAQDA = Computer Assisted Qualitative Data Analysis

CHC = Community Health Council

CIN = cervical intraepithelial neoplasia

CRC = Cancer Research Campaign

CRE = Commission for Racial Equality

DoH = Department of Health

EMHAP = Ethnic Minorities Health Action Project

FPC = Family Planning Clinic

GP = General Practitioner

GPs = General Practitioners

HEA = Health Education Authority

ICRF = Imperial Cancer Research Fund

NAHAT = National Association of Health Authorities and Trusts

NHS = National Health Service

RHA = Regional Health Authority

S.S.S. = Secretary of State for Scotland

TV = Television

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South Asian women and Access to Healthcare

1.1 Introduction

This thesis is about access to healthcare for women of South Asian heritage living in Edinburgh. I focus on access because although equal access to healthcare is a central welfare ideal, inequalities in access to healthcare have been a source of concern to health professionals and the general public throughout the life of the NHS and a topic of central interest in medical geography. I concentrate on minority ethnic groups because although inequalities in access to healthcare are known to hinge around 'race' and ethnic difference, the topic has been poorly researched (Ahmad, 1994). Few studies have explored minority ethnic groups' experiences and perspectives in relation to health and health services (Douglas, 1992). Indeed, minority ethnic groups are more often stereotyped as harbingers of disease and as a drain on health service resources rather than as groups whose healthcare opportunities might be limited in a number of ways. I direct my study towards minority ethnic women because although women's health is a topic of increasing interest among academics and the general public, minority ethnic women's access to healthcare is poorly understood, even though minority ethnic women are likely to be doubly compromised on account of ideas about 'race' and gender difference. My focus on South Asian women in Edinburgh builds on the small number of studies in this field in Scotland.

The aim of this chapter is to outline the background to my study. I present a critical review of existing research to make the following points. Firstly, I argue for a broader conceptualisation of the notion of access to healthcare. Secondly, I argue for a wider conception of healthcare, as something more than service provision. Thirdly, I argue that these broader notions can only be appreciated with reference to the perspectives and experiences of people, in this case South Asian women. Fourthly, I introduce some dominant ideas about minority ethnic groups and healthcare, their health needs and service requirements. Finally, I introduce my own research project which is designed both to criticise and to fill some gaps in the existing literature on minority ethnic groups and health.

I focus on South Asian women's access to three different healthcare arenas - healthcare outside services, the GP service and cervical cytology (i.e. informal care, a general mainstream health service and a targeted preventative screening service).

1.2 Conceptualising Access to Healthcare

In this section I seek to develop the theme of access to healthcare. Most of the literature on this theme focuses on health services. Taking this as a starting point, I will argue for a broader conceptualisation of access and a broader notion of what constitutes healthcare. I argue firstly, that access is more than the uptake of, and physical distance from, caring services and secondly, that healthcare is more than just the use of health services. To explore these broader notions it is also necessary to reconsider how we measure access and define healthcare. I argue that traditional quantitative and objectivised approaches need to be complemented by more in-depth qualitative work. Therefore, my study aims to gain a deeper understanding of access to healthcare which is sensitive to the perspectives and experiences of South Asian women.

The literature on access to healthcare largely ignores minority ethnic groups. The work that does exist points primarily to the disadvantage of minority ethnic groups with regard to access to health services. A number of quantitative studies show that minority ethnic groups' patterns of health service use may differ from other users and that their access, measured in terms of uptake, is low. For example, a study by Gillam *et al.* (1989) on GP use shows lower consultation rates for mental disorders, depression and anxiety among all minority ethnic groups, especially among South Asian women, compared to white users. It also shows that South Asians consult more frequently than white users for other conditions such as upper respiratory tract infections. Fenton's (1986) work shows evidence of low uptake and poor satisfaction with services, especially secondary care (i.e. hospital based care), by minority ethnic groups. In addition, studies by Lumb *et al.* (1981) and Clarke and Clayton (1983) show differences in the uptake of maternity services by South Asian women compared with non-Asian women.

Despite some useful work on uptake it is difficult to pinpoint why inequalities in access, even when measured in conventional terms, exist and persist. Therefore, if we are to explore access to healthcare for minority ethnic groups further we need to overcome some important limitations in the existing literature. The main limitation, in my view, is that little

information exists on minority ethnic groups' own perspectives on, and experiences of, healthcare. This general invisibility of minority ethnic groups in welfare services is commented on by Ahmad (1993a: 23) who refers to the 'editing out' of minority ethnic groups which he identifies 'as a focus for research and researchers'. He and others call for 'a social research agenda' concentrating on minority ethnic groups' perspectives on health and healthcare provision (Ahmad, 1993a: 31) and for a focus of interest to be minority ethnic groups themselves (Bhopal, 1992). Ahmad (1993a) also calls for a focus on black women that empowers them to define their own priorities.

Access to healthcare is usually thought of in terms of spatial proximity to caring services, that is the physical distribution, patterning and positioning of services, as well as service uptake, that is rates of service use (Knox, 1987; Joseph and Phillips, 1984). I will argue that this allows only a partial understanding of access to healthcare for minority ethnic women.

Research which conceptualises access in terms of physical distance to services (spatial accessibility) and service uptake does not allow an understanding of access that is sensitive to a range of differences or inequalities among social groups. It tells us nothing about the concerns or experiences of people themselves. According to Blaxter (1985) often it is the patients' perceptions which are the key to understanding patterns of service use and I would add patterns of healthcare more generally. Access in terms of physical distance also reveals little about the quality or effectiveness of care (Farooqi, 1993) or about the appropriateness of healthcare in relation to personal need. I therefore adopt a conceptualisation of access which moves beyond uptake and physical distance to caring services and which draws attention to the way healthcare and health services are experienced and perceived by individuals.

When we broaden the concept of access we also reconceptualise notions of healthcare. When access is thought of narrowly as uptake it is based on measures of contact with health and welfare services. However, healthcare is more than just the use of health services and occurs in a number of different arenas. Most healthcare takes place outside services and includes health maintenance as well as healthcare actions in ill health. In addition, healthcare is not only for women it is also provided by them. Women are central healthcare providers, both formally and informally, as well as consumers. A broader conceptualisation of access allows us to consider healthcare in its widest (and therefore most useful) sense and

to include not only healthcare involving service use but also, what I term, healthcare 'outside services' (i.e. healthcare not involving health service use).

Support for a broader conceptualisation of access to healthcare comes from a range of different studies. Firstly, from studies that have suggested that the healthcare experiences of minority ethnic women may be qualitatively different from those of majority ethnic women (see below) and from studies that emphasise a need to recognise that different women are treated differently within the welfare state (Mama, 1992; Bhavnani and Coulson, 1986). For example, studies by Clarke and Clayton (1983) on ante-natal care, by Ahmad *et al.* (1991b) on General Practice and Madhok *et al.* (1992) on aspects on non-clinical hospital care, suggest that the quality of care gained by South Asian service users is poorer than for non-Asian service users.

Secondly, there is increasing awareness that services are not meeting the needs of minority ethnic groups. This has included government acknowledgement of differences in health experiences between ethnic groups (DoH, 1993, 1992). However, studies on minority ethnic groups show that despite the long-term presence of minority ethnic groups in the UK, there is still insensitivity to their health, social and cultural needs, both in policy and in provision (Atkin *et al.*, 1988).

In order to provide insight into factors constraining and enabling access to healthcare for South Asian women my study focuses on access to three different healthcare arenas - healthcare outside services, the GP service and cervical cytology.

1.3 The Women's Response - the importance of lay perspectives and advocacy approaches

I have argued that research sensitive to the healthcare needs and experiences of marginalised groups requires a broader conceptualisation of access and healthcare than is usual in medical geography and sociology. This broader conceptualisation also means that there is a need to start with people's own views and health experiences. This is the starting point of my study. For minority ethnic women, however, questions and understandings about access to healthcare are too often constructed around stereotypical assumptions and anecdotes (Bowler, 1993a, 1993b; Pearson, 1989). This chapter argues that this reproduces questionable ideas about 'race' and cultural difference and leads to inefficient service planning. My argument is, therefore, that by starting with the perspectives and experiences

of minority ethnic groups themselves it is possible to challenge conventional wisdoms and to enhance access to healthcare for minority ethnic groups.

Previous research has paid little attention to the points of view of minority ethnic healthcare users who have rarely been consulted about their views of provision or their own general health (Howlett *et al.*, 1992; Atkin, 1991; Atkin *et al.*, 1989; Ahmad *et al.*, 1989a; NAHA, 1988; Donovan, 1986). As noted above, much of the existing work on access has centred on service use, this has focused on the attributes of minority ethnic service users rather than on the attributes of services themselves. I would argue that access to healthcare involves an examination of both the service side and user side of healthcare.

In order to make progress in thinking about access to healthcare, it is the aim of my study to find ways of understanding the experiences and perspectives of minority ethnic groups and ways to document their concerns about the attributes of health services and about healthcare in its broadest sense. In this, I am taking up the concerns of those who argue that debates on service delivery need to become situated in the realities of minority ethnic groups' lives (Atkin *et al.*, 1989).

My study focuses on minority ethnic women, specifically South Asian women, as users of healthcare. My emphasis on minority ethnic women's views and experiences parallels a number of themes in the literature on healthcare and service use. Firstly, there is a general need to evaluate mainstream healthcare entitlements from the point of view of the user (Popay and Williams, 1994; Atkin, 1991). User views, according to Atkin *et al.* (1988) will raise the status of the individual and his/her lay knowledge in defining their own health needs and in the provision of appropriate and effective care. Secondly, the need to focus on minority ethnic women's views and experiences parallels a need to recognise that women themselves have valid interpretations of health and ill health. According to Roberts (1992), women's views are a largely untapped area of expertise in women's health. Thirdly, user views align with studies which advocate that people's knowledge should inform public policy. Roberts (1992) argues that to be valuable, policy arising from research needs to be connected with the lives of those towards whom policy is directed. This is especially important for women because men have created most medical knowledge and because women provide most of the care giving in society (Doyal, 1991). Fourthly, a focus on minority ethnic women's views parallels a shift in the context of provision and in the relationship between the provision of public services and actual and potential recipients of

them. This includes a drive to 'involve or listen to local people' (Popay and Williams, 1994: 75) in assessing health and healthcare needs. Also it parallels shifts in the nature of the division between health professionals and health service users, from expert and lay person, to two experts each possessing valuable health knowledge (Nettleton, 1995). So called, lay health expertise (i.e. common-sense experience) has often been derided in the past and professional advice is often seen as more objective and rational (Nettleton, 1995; Doyal, 1991). According to Doyal (1991: 285) women's experiences should be given much greater status in 'what is effectively a hierarchy of knowledge.'

My study builds from others that have used approaches to enable South Asian women to speak (e.g. Bowes and Domokos, 1996, 1995a, 1995b, 1995c, 1993), and it complements the findings of other studies on aspects of South Asian health and health behaviour (Bowes and Domokos, 1995c, 1993; Currer, 1991; Donovan, 1986; Ahmad, Kernohan and Baker, 1991a, 1989b). It also provides evidence that challenges a number of existing assumptions about South Asian women's health behaviours, health needs and about the enablements and constraints on access to healthcare for South Asian women. It emphasises that the health behaviours and attitudes of women need to be uncovered if women's needs and concerns are to be identified and acted upon.

Having emphasised that user views are critical in debates on minority ethnic groups and access to healthcare 'to alter its present assumptions' (Atkin, 1991: 161), the next two sections examine debates about minority ethnic groups and healthcare in more detail.

1.4 Perspectives on South Asian women and healthcare

Although the majority of research on health and healthcare in Britain has tended to be insensitive to cultural, gender and 'race' difference, there is a small but growing literature which is more alert to the difference that these attributes make. However, when the subject is women from minority ethnic groups, research has tended to tackle culture, 'race' difference and gender difference separately, often taking one at the expense of others. In this section I assess the strengths and limitations of these approaches and consider their implications for understanding access to healthcare for minority ethnic groups. The challenge they raise is to find ways to grasp the interplay of culture, 'race' and gender difference in order to make progress in understanding the healthcare experiences and

perspectives of South Asian women and their access to healthcare. My study aims to do this in three different healthcare arenas.

1.4.1 Constructions of Culture and Access to healthcare for South Asian women

I have argued above that the literature on access to healthcare largely underplays issues of difference among social groups. Where difference is recognised analysts have been preoccupied with cultural explanations that draw on constructions of minority ethnic culture. In this section I consider the nature of explanations which draw on constructions of culture and assess their wider implications for understanding minority ethnic groups' access to healthcare. In doing so I make the distinction between constructions of culture and culture as people's world views. The former are used uncritically in many studies, are used to shape public policy and contain a limited understanding of minority ethnic groups' health experiences. Studies then, have tended to talk about minority ethnic groups' culture in an uncritical way. Recent discussion of the new racism (see section 1.4.2) shows that culture is a common euphemism for ideas about 'race' difference in a discourse which perpetuates the idea of 'race' and reproduces inequalities between racialised groups. Given the dominance of cultural perspectives in the literature on minority ethnic groups and health together with the uncritical use of the idea of culture in this literature, links to the new racism are virtually inevitable. These will be flagged below, but discussed more fully in section 1.4.2.

The following examples are typical of a range of culturally deterministic approaches to health and healthcare among minority ethnic groups. They show a focus on 'different' healthcare practices and on 'different' factors in explanations of particular health concerns for minority ethnic groups compared to the majority ethnic population. Goel *et al.* (1981) explored the problem of rickets. They explained the increased incidence among South Asians in terms of firstly, the un-British eating and living habits of South Asians and secondly, a genetic deficiency that inhibits absorption of vitamin D and its synthesis from sunlight. For Goel *et al.* (1981) the solution to the problem lay in the adoption of a Western diet. Their explanation, therefore, failed to highlight the link between poverty and the incidence of rickets among South Asians, even though poverty had already been associated with rickets among non-Asians. Another example of the cultural overemphasis in explanations of the health experiences of minority ethnic groups is Sutton's (1990) work on contraceptive use in Newham, London. Sutton (1990) found that older South Asian women

preferred to use condoms and that oral contraceptives were favoured by non-Asians. Sutton (1990) then blames high perinatal mortality rates among South Asians on South Asian contraceptive practice and ignores the fact that Newham is one of the most deprived inner city areas in London and that there is a well documented link between deprivation and perinatal mortality. My final example is that of Qureshi (1990a, 1990b), a GP who writes about minority ethnic groups' health problems. He presents extensive descriptions of differences in health experiences peculiar to minority ethnic groups. This practice is integral to the culturalist approach (Pearson, 1986a). Qureshi uses fragments of facts and stereotypes that are represented as definitive and like the two examples above, explanations for particular health problems or practices are somewhat removed from the experiences of minority ethnic groups. They also lack 'political insight' (Ahmad, 1993a: 2) as the following quotations show. Writing on family planning and culture Qureshi argues that:

'unlike ethnic minority patients, ethnic English women are more aware of the topics of the day discussed on TV, radio and in the newspapers. They will have more confidence in taking the pill and will not hesitate to question the doctor about its side-effects...An English patient likes to discuss an issue with her doctor, whereas an ethnic minority patient prefers a simple explanation rather than a long discussion.' (Qureshi, 1989: 114)

And on dietary habits:

'whereas English people may use a knife and fork, Afro-Asians may use clean hands for eating. According to religious and cultural customs they wash their hands before eating, and after eating they...rinse their mouths thereby cleaning teeth. It is said that this habit is the reason for their strong teeth. No wonder they can tear the meat with their teeth and do not need cutlery - which, in a large family, they sometimes cannot afford anyway...' (Qureshi, 1989: 24)

These 'facts' are contained in 'hitch-hikers' guides to a range of minority ethnic cultures (Sheldon and Parker, 1992b: 66) and according to Johnson (1992), form part of the 'isn't it interesting' school of multiculturalism. Ahmad (1993a), Howlett *et al.* (1992) and Johnson (1992) are especially critical of Qureshi's work which is used in guides for practice in a multicultural society.

Culturally deterministic approaches construct and explain health status, healthcare experiences and attitudes in terms of cultural differences. However, constructions of minority ethnic culture are paralleled by an uncritical view of white society as the norm (Pearson, 1986a). Minority ethnic culture then becomes measured against that norm. This has meant that minority ethnic culture is seen negatively and that cultural difference is equated with deviance or inferiority and is identified as 'a problem'. This has a number of

implications for understanding access to healthcare. Firstly, it has led to the construction of minority ethnic groups' health problems and key concerns without understanding the experiences of the groups themselves. Secondly, where culture is assumed to determine minority ethnic groups' health status, attitudes and behaviours, minority ethnic groups are seen to deviate from 'good' health and healthcare. The health behaviours of minority ethnic groups are often regarded as unconventional. 'Experts' often note that black people's morbidity and response to health and ill health is different to the majority population. This difference then becomes equated with deviance.' (Atkin, 1991: 160). In terms of service use, minority ethnic groups are assumed to use services in unconventional ways on account of constructions of their culture. Cultural difference is depicted as denying minority ethnic groups equal access to services (Douglas, 1992) and minority ethnic culture is seen to be the problem rather than an inflexible and ethnocentric service or discrimination, for example. This view, in turn deflects attention from the challenge of exploring minority ethnic groups' own perspectives on, and experiences of, access to healthcare.

Culturally determinist explanations also fail to take into account a variety of factors that I would argue are central to understanding access to healthcare. One of the most important criticisms is that culturally deterministic approaches deflect attention from 'structural' explanations for inequalities in access to healthcare, healthcare experiences or differences in health outcomes. They have done little to challenge the structural constraints on access to healthcare. Douglas (1992) and Atkin (1991) argue that the focus on minority ethnic culture diverts attention from the wider power relations in society, especially those between minority ethnic and majority ethnic groups. This focus does not consider 'race' as a social construct (Douglas, 1992) or ideas about gender difference and the effects of these factors on access to healthcare.

Douglas (1992) is critical of the literature examining minority ethnic groups' health experiences. She shows that although some studies on maternity services, for example Currer (1986) and Homans (1980), have highlighted areas of discrimination in maternity services, their main emphasis, however, has been the effects of culture on women's concepts of health and experiences of healthcare. Mama (1992) discusses the changing meanings of ethnicity and culture in research. She argues that racism has been reduced to cultural misunderstandings and has been depoliticised. Here ideas about 'race' difference have

become clothed in the language of culture. This is what is referred to as the new racism (discussed in 1.4.2)

Culturally deterministic research has a number of implications for questions about access, responses to inequalities in access to healthcare, and for understanding the health and health service needs of minority ethnic groups and health service responses. It has also affected the determination of research foci. These implications are examined below.

Questions about access

Culturally deterministic research has shaped our questions about access to healthcare. In particular, such approaches concentrate on differences rather than commonalities in experiences between different ethnic groups. The particularity of minority ethnic groups' concerns and healthcare behaviours means that questions are asked of black women that are not asked of white women (Phoenix, 1990). Further, health issues become redefined and a different range of explanations is used for minority ethnic groups than for the rest of the population. This practice helps to maintain the social construction of black people's health behaviours as deviations from the norm (Ahmad *et al.*, 1989a) and it emphasises that the health behaviour of minority ethnic groups needs justification (Phoenix, 1992). There is, however, insufficient evidence to suggest that the health attitudes and actions of South Asian women are either the same or differ significantly from those of other women. An overemphasis on the cultural determinants of health behaviours obscures the shared dimensions of health experiences between people. For example, it ignores influences on health and health behaviour such as socio-economic status (Fenton *et al.*, 1995), housing conditions, income and access to health services (Rathwell and Phillips, 1986). Although these factors are seen as important in understanding health inequalities generally, they have tended to receive little attention when the main consideration is the health of minority ethnic groups. I would argue that it is problematic if understandings of access to healthcare are based on limited understandings of the factors affecting minority ethnic groups' healthcare experiences and perspectives.

Responses to inequalities in access

The overemphasis on constructions of culture also has implications for responses to inequalities in access to healthcare. If social realities are explained and constructed in terms of cultural differences, then solutions to healthcare inequalities or problems are also

perceived in cultural terms. This means that the cause of problems, for example, becomes located in minority ethnic groups themselves (Atkin, 1991) and that minority ethnic groups are blamed for their own health, health problems and inequalities in access to healthcare.

Culture blaming has a number of wider implications. Firstly, it leads South Asian women, for example, to be seen as a problematic category and perpetuates the idea that minority ethnic culture is 'bad' for health. Secondly, it reinforces the pathologisation of minority ethnic groups and health issues, where such groups are associated with death, depravity and disease (Ahmad, 1994) and are seen as dangerous to their own health (Ahmad, 1993a). Thirdly, culture blaming reinforces an ideology which views minority ethnic groups as second class citizens who have an inferior image in health services (Pearson, 1986b). Fourthly, if minority ethnic groups are seen as always causing problems then access to care may be more difficult to negotiate. Fifthly, it also reinforces an ideology claiming superiority of Western over non-Western culture and tradition (Ahmad 1993a).

Finally, culture blaming also means that the burden of healthcare and problems of access become shifted onto minority ethnic communities. The onus for change lies then with the groups themselves and their alien and deficient culture (Sheldon and Parker, 1992b). This also has implications for responses to inequalities in access to healthcare. Atkin (1991) argues that a preoccupation with cultural practices results in implicit racism in policy discussion. The classification of minority ethnic culture according to a particular white norm means that minority ethnic culture becomes a problem that needs to be regulated. Cultural approaches mean that policy and explanations are based on a deficit model, where access to healthcare may be improved by stamping out or regulating harmful customs and practices in minority ethnic culture. This leads Dutt (1990) to argue that minority ethnic groups then experience the controlling aspects of welfare provision more than the caring aspects.

Health needs

The overemphasis on constructions of culture also has implications for understanding the health needs of minority ethnic groups. Often it is argued that the healthcare needs of South Asian women are distinctive due to culture. This brings with it the danger of accepting and promoting cultural stereotypes and ideas about 'race' difference to the detriment of South Asian women, for example, and their needs. The overemphasis on constructions of minority ethnic culture means that the health needs of minority ethnic groups remain under-

investigated. It also means that South Asian culture, for example, is assumed rather than investigated (Bowes and Domokos, 1993).

Stereotypes are central to understandings of South Asian women's access to healthcare. They construct South Asian women as distinct by virtue of their culture and question women's abilities and cultural attributes. According to Ahmad (1994) the effects of stereotyping on access to healthcare remain under-investigated. This occurs despite other work which shows that stereotyping has a long history for minority ethnic groups in their use of health services (Littlewood and Lipsedge, 1989). Brah's (1992, 1993) work shows that stereotypes of South Asian women are contradictory and operate in many areas of society. South Asian women are seen as oppressed, vulnerable, controlled and in need of liberation, they are victims whilst posing a threat as the bearer of those who threaten western civilisations. They are dirty, ugly and undesirable and at the same time sexually available. Stereotypes affect understandings of the health needs of minority ethnic groups and have adverse effects on access when 'sedimented into collective common sense' (Brah, 1992: 448) and translated into policy and practice. The influence of stereotypes has been highlighted in studies on minority ethnic groups' health service experiences. For example, Bowler (1993a, 1993b) makes the important link between the employment of stereotypes by health professionals and the quality of care gained. She shows that stereotypes of South Asian women in midwifery reflect four main themes: difficulties in communication; lack of compliance with care and abuse of services; the tendency to make a fuss about nothing; and a lack of maternal instinct. Her work shows how these stereotypes affect the quality of care that women are thought to want and deserve, and contribute to inequalities in healthcare between patients. Also Evers *et al.*'s (1989) work on community service provision shows that comments from service providers include the assumption that South Asians do not need help as they have family and community support networks, and that minority ethnic groups are ignorant about available services and need educating. Again stereotypes affect understandings of South Asian groups' health needs.

Health service needs and responses to need

The examples cited above show that culturally deterministic research and the stereotyping of the health needs of minority ethnic groups obscure an understanding of the health service needs of South Asian women. My main concern is that previous studies have been more concerned with the attributes of minority ethnic groups and their 'imported culture' than

with the attributes of health services or with the experiences of minority ethnic groups in health services.

The construction of minority ethnic health needs has affected the response of health services to the needs of minority ethnic groups in a number of ways. Firstly, if it is assumed that the culture of the user is 'at fault' then there is little need to look at the attributes of health services. Secondly, this means little reflection on health service practice has taken place. Thirdly, the construction of minority ethnic groups' health needs and the pathologisation of minority ethnic culture means that services are distanced from playing a part in the inequalities in access to healthcare that may exist between ethnic groups. Inequalities and patterns of access become located in a mismatch between minority ethnic groups and service provision. I argue, therefore, that the construction of minority ethnic health needs as a product of culture obscures understandings of and responses to the health service needs of these groups.

'...providers of services often assume that they operate from a culture free stance which leads to the problematising of those clients or patients assumed to have different cultures. Thus in seeking to explain differential access to services research has tended to focus on the clients rather than on institutions' (Sheldon and Parker, 1992b: 108)

The construction of minority ethnic groups' health needs and the distancing of explanations of health needs and inequalities in access from the attributes of services, absolves the health service of its responsibility to improve access and to provide appropriate care and ethnically sensitive practice. In turn, this 'allows' minority ethnic groups' views and experiences to remain unheard and lets health planners 'off the hook' by allowing services to 'carry on as usual' (Pearson, 1989: 78). In effect, issues of minority ethnic groups and access to healthcare become a non-concern and non-action is justified. Minority ethnic groups' health problems and health service experiences are marginalised and sidelined and health service responses are incomplete and may not meet needs.

Research issues

The overemphasis on constructions of minority ethnic culture, and the construction of minority ethnic groups' health needs and problems have been reflected in the identification of research issues. This has compounded conventional understandings of minority ethnic groups and healthcare and has implications for understanding minority ethnic groups' experiences of healthcare as well as for strategies to improve access to healthcare.

Early research on health status focused on a small number of areas. It was 'disease centred' and 'clinically biased' (Ahmad, 1993a). This type of research has a number of implications for explanations of minority ethnic groups' patterns of healthcare. Firstly, it reified 'race' and ethnicity (Sheldon and Parker, 1992b) and used categories as a biological or genetic tool for explanatory purposes. This did little to focus on 'race' difference as a social construct that is linked to the structures and relations of power (Rathwell and Phillips, 1986). In addition, it provided little understanding of the concepts underlying the categories used or their operationalisation (Sheldon and Parker, 1992b) and did little to show how ideas about 'race' difference are created, reproduced or challenged (Bhavnani, 1993).

Secondly, many epidemiological studies were underlined by a biomedical model of health which focused on ill health and disease among minority ethnic groups as its central concern. Often studies concentrated on a number of distinctive, exoticised diseases and conditions or interesting cultural quirks (Bhopal, 1989) reflecting the prevailing social perspectives where minority ethnic groups were seen as 'dark strangers' with exotic cultures and diseases (Douglas, 1996). Studies have focused on tuberculosis, inherited blood disorders such as sickle cell anaemia and thalassaemia (Davis *et al.*, 1981), rickets (Goel, 1981), hypertension, and diabetes (Cruikshank *et al.*, 1980). Some have focused on perinatal mortality (Lumb *et al.*, 1981) or distinctively South Asian health practices and medicines such as *hakims* (meaning scholar but which has a diversity of meanings including doctor) (Aslam *et al.*, 1981). Other studies have criticised a focus on particular customs and cultural factors as dangers to health. A concentration on cultural practices such as the use of *surma*, a black powder applied around the eyes, used for medical and ritualistic purposes which sometimes contains lead sulphide (Pearson, 1986b), as well as the South Asian diet (Douglas, 1992), and *purdah* (Curren, 1986) have been the focus of some concern. Explanations of ill health that focus on distinctive patterns of living, such as the effect of consanguineous marriages on obstetric outcome (Ahmad, 1994, 1993a), have also been criticised. For Ahmad (1993a) this is a continuation of the West's fascination with and fear of what the West has defined as exotic people, exotic customs and exotic diseases and a tendency to reduce complex phenomena to cultural or genetic factors. Such an approach does little to examine access to healthcare for minority ethnic groups and smacks of tokenism as such studies include minority ethnic groups as 'a topic' but do not recognise their views or experiences.

Of particular relevance to my study, culturally deterministic accounts focus on the disease at the expense of an examination of access to healthcare in its broadest sense. My central

criticism is that although disease centred research has highlighted different patterns of health and disease among minority ethnic groups, differences in health status have been disconnected from individual experience of and perspectives on health and ill health. This is what I mean by access in its wider sense. It is also disconnected from an examination of other oppressions and from the structural factors that might affect minority ethnic groups' experiences of and attitudes to healthcare. Critics argue that early studies often linked the prevalence of health problems to individual behaviour, culture or linguistic problems rather than broader structural and service issues (Douglas, 1992; Donovan, 1984; Johnson, 1984).

The scientific rigour of much 'disease centred' research has been questioned on four counts. Firstly, the approach ignores the multifactorial nature of disease and the complex issues determining health status, experiences and behaviour (Ahmad *et al.*, 1993a, Douglas, 1992). Secondly, critics have challenged the use of Western models of health, in particular the biomedical model of health and disease. Ahmad, (1993a) and Sheldon and Parker (1992b) criticise the focus on disease or illness at the expense of the experiences of groups and Bhopal (1992) is critical of studies which, in searching for a new perspective on the disorder, mean that minority ethnic groups become peripheral. Thirdly, critics have challenged research which has meant that the realities of people's lives become collapsed into indicators of health experiences (Sheldon and Parker, 1992b; Bhopal, 1989). Fourthly, critics argue that the medical emphasis on particular diseases described above, may not necessarily be priorities for minority ethnic groups themselves (Pearson, 1986b). Finally, some criticism has centred on the impact of 'disease centred research' on people's lives. According to Sheldon and Parker (1992b) its findings have not been used to support those experiencing disease, improve understanding of the management of health and ill health or to evaluate strategies to improve healthcare. Instead:

'The tendency to collect routine ethnic data and include ethnic variables in an *ad hoc* and uncritical way...may help transform minorities into mere statistical categories and produce data and findings which reinforce stereotypes' (Sheldon and Parker, 1992b: 104)

I would argue that minority ethnic groups must not be excluded from defining their own health needs, healthcare experiences and realities. There is a danger that they have become the objects of research which makes little difference to their lives and well being. This reinforces my point that user views are central to understandings of access to healthcare.

A number of authors (Ahmad, 1993a; Stubbs, 1993; Sheldon and Parker, 1992b; Pearson, 1986a) have questioned the ability of culturally reductionist research to make a difference to

minority ethnic groups' lives and to improve access to healthcare. They have also questioned its contribution to understandings of ill health and improvements in healthcare. Research has become divorced from 'committed and positive action' (Pearson, 1986a: 101) where forms of cultural reductionism would not be 'tolerated in other areas of medical and social research' (Ahmad, 1993a: 11; Sheldon and Parker, 1992b). Douglas (1992) and Anionwu (1993) cite the example of sickle cell disorders and minority ethnic groups where incidence rates have been the subject of extensive study, but this has led to little initial research on the experience or development of support services for sufferers.

The construction of minority ethnic groups' health problems means that the literature is skewed in favour of the interests of health professionals rather than the concerns of minority ethnic groups themselves, where the latter have little to do with setting the research agenda (Douglas, 1992; Webb, 1982). The colonisation of minority ethnic health issues and realities (Ahmad, 1993a) has resulted in what Ahmad *et al.* (1989c: 54) term an 'intellectual apartheid', where minority ethnic groups are excluded from studies about themselves. This is not good for science and not good for improving the health status of South Asians (Ahmad, 1993a).

There have been some attempts to challenge the overemphasis on constructions of culture as a determining factor in explanations of minority ethnic groups and healthcare. The stress on and use of such ideas about culture have been criticised by writers on healthcare (e.g. Bowes and Domokos, 1995a, 1993; Ahmad, 1994; Douglas, 1992; Howlett *et al.*, 1992; Cox and Bostock, 1989; Phoenix, 1992, 1990; Fenton, 1987; Pearson, 1986a, 1986b; Rathwell and Phillips, 1986) and outside (e.g. Lawrence, 1982), in particular by black feminist writers (Mama, 1992; Brah, 1992; Parmar, 1982; Bryan *et al.*, 1985).

Criticism has focused on the stereotypical constructions of culture used in research, where minority ethnic culture is reduced to a set of things such as a distinctive diet, dress or consulting a *hakim*, and where culture has been assumed rather than investigated (Bowes and Domokos, 1995a). Pearson (1986b) criticises racist notions of ethnicity and culture and their use to explain healthcare patterns and to uphold the view that problems exist as a result of mismatches between minority ethnic and majority ethnic cultures. She criticises pluralist perspectives which assume that different ethnic groups and their cultures meet on equal terms and which obfuscate the wider power relations between groups in society. Phoenix (1992) criticises notions of minority ethnic culture that seem removed from the lived

experience of minority ethnic groups in Britain. She also argues that culture is linked to broader structural forces affecting all people's lives and is not a discrete entity. Further, Douglas (1992) criticises culturally deterministic approaches because they deny the variety of experiences that exist, and ignore variations in ethnicity and gender and the heterogeneity, among minority ethnic groups. Finally, Ballard (1992) criticises the pathological, deprivationist 'static', over concretised and constraining representations of minority ethnic culture and Lawrence (1982) argues that these cultures have been seen as backward looking, negative and traditional. As a result of this process, the dynamism of culture is lost (Ahmad, 1993a; Brah, 1992) and culture is devalued. According to Brah (1992: 69) studies:

'...operate within a totally reified concept of culture as some kind of baggage to be carried around instead of a dynamic and potentially oppositional force.'

The effects of culture (appropriately conceptualised) on access to healthcare cannot be denied, however, they must be investigated rather than assumed (Bowes and Domokos, 1995a). My aim is to move away from stereotypical notions of culture and away from a focus on cultural distinctiveness and culture as a determining factor in South Asian women's access to healthcare. As I have argued this thinking is overplayed in the literature on minority ethnic groups and healthcare. Culture is people's 'world view' (Bowes and Domokos, 1996, 1995a) which draws on a shared fund of ideas or culture and an individual's lived experience (Bowes, Dar and Sim, 1995). In this sense culture is a resource that enables people to do things and to respond to problems. It also influences health attitudes and actions and is valuable in negotiating access to healthcare. Culture can be seen as dynamic and fluid (Brah, 1993), formed and reformed (Sheldon and Parker, 1992b), and as a nurturing and sustaining force (Ahmad, 1993a). Ballard's (1992) discussion aims to reassert the role of culture in understanding the experiences of minority ethnic groups. He tries to move away from discussions that emphasise racism and deprivationism as primary factors which determine the lifestyle and life chances of minority ethnic groups. His discussion shows that people's world view guides their behaviour and shows that people are active agents rather than passive victims in the face of constraints.

This section has questioned the salience and use of culture as a determining and explanatory factor in minority ethnic groups' access to healthcare. It has argued against the misuse of cultural explanations not cultural explanations themselves. This is supported by studies which criticise the use of constructions of minority ethnic culture and which argue that

culture should be seen as people's world views. Explanations drawing on stereotypical constructions of culture have contained limited understandings of the health experiences and health needs of minority ethnic groups and have limited responses to those needs.

1.4.2 Ideas about 'Race' and gender difference and Access to healthcare for South Asian women

I have argued that women's experiences and perspectives are central to understandings of access to healthcare but that these understandings have been hampered by disease centred research and cultural determinism. Other studies in other subject areas have challenged the overemphasis on constructions minority ethnic culture and urge a move toward a conceptualisation of access that is sensitive to the full range of experience in the population. In this section I will consider studies on 'race' and health and on gender and health and other studies which challenge the separation of forms of oppression such as ideas about 'race' or gender difference in understandings of minority ethnic women's experiences. My argument is that an examination of access to healthcare for South Asian women must take into account the cultural, 'race' and gender dimensions of access to healthcare.

An overemphasis on explanations for healthcare practices and beliefs that draw on stereotypical constructions of culture in the literature on minority ethnic groups and healthcare means that the effects of ideas about 'race' and gender difference on access to healthcare have become submerged. In addition, studies on 'race' and health have generally ignored gender difference and culture. Also, research on women and healthcare has generally ignored both the 'race' and culture dimensions of healthcare experiences. This contributes to the invisibility of minority ethnic women in two areas of research. Referring to research on minority ethnic women Bhavnani (1993: 35) argues that someone is either a member of a racialised group or a woman and is defined 'into or out of one of these categories'. However, this does not allow for differences in the life experiences of minority ethnic women who experience both ideas about 'race' difference and ideas about gender difference. This means that minority ethnic women are doubly marginalised in ways that we know very little about.

Some authors have argued for an examination of the relationship between racism and sexism in the lives of minority ethnic women in the UK, but very little of this work addresses healthcare (but see Bowes and Domokos, 1995a, 1993; Mama, 1992). Few studies highlight the differences or similarities in minority ethnic women's healthcare experiences compared

to those of majority ethnic women or show that such experiences may be structured by 'race' difference as well as by gender difference and class.

Some work has shown intersections between racism and sexism in other areas of life and this provides a useful starting point. For example, Brah (1993, 1992) and Anthias and Yuval-Davis (1993) focus on employment, Brah (1992) and Mirza (1992) focus on education, Bhavnani and Coulson (1986) consider immigration and nationality legislation and Ramazanoglu (1989) focuses on the research process. In addition, a number of anti-racist authors highlight the specificities of minority ethnic women's situations (e.g. Allen 1987; Bhavnani and Coulson, 1986; Carby, 1982; Parmar, 1982). For example, Brah (1992) shows that black women's labour market position is affected firstly, by gender ideologies which influence the kind of work that women do and secondly, by their structural location as black workers which constrains the scope of the labour market positions they occupy. Mama (1992) focuses on black women's relationship to the welfare state. She looks at mental health and presents an analysis of the position of black women as users and workers in the NHS. She shows how 'race', class and gender divisions are reproduced in different areas of life and are manifested in the allocation of health and welfare resources and in service delivery. I would argue that access to healthcare must also be conceptualised within these wider inequalities and struggles.

As noted above, studies focusing on ideas about 'race' and health are generally gender blind. Ideas about gender difference have not been well tackled in the literature on minority ethnic groups in the UK, or in the literature on minority ethnic groups and healthcare (e.g. Hennings, 1993; Donovan, 1986). Donovan's (1986) study, for example, centres on the health experiences of Asian women and Afro-Caribbean men and women in East London. However, she does not adequately consider ideas about gender difference and concludes that her informants' lives are mediated by socio-economic systems and racism, and less by culture. Some authors argue that racism is a primary determinant in minority ethnic women's lives (e.g. Douglas, 1992). I would argue that to treat racism as an autonomous social process and as the sole factor in determining explanations of access to healthcare for minority ethnic women, raises similar problems as culturally deterministic explanations in debates on minority ethnic groups and healthcare. Studies must, therefore, be designed to examine the effects of ideas about gender difference if we are to develop a more complete picture of South Asian women's access to healthcare.

The literature on women's health, however, is generally 'race' blind. 'When women have been written about it is almost exclusively white women...the term has been used as if it were colour neutral' (Phoenix, 1992: 76). In general, work on women's health has neither understood nor challenged the position of minority ethnic women and healthcare. Bhavnani (1993) for example, writes of feminist research:

'Even when differences of interest are acknowledged by some feminists, it is rare for such differences to be actively engaged with - mere acknowledgement seems to be enough.' (Bhavnani, 1993: 31)

The literature on majority ethnic women and health has revealed the importance of gender difference as a factor in healthcare (Doyal and Elston, 1991; Doyal, 1985a, 1985b; Roberts, 1985; Graham, 1984). In the light of my criticism I would argue that studies need to temper the primacy of gender by exploring other factors which shape women's experiences and that they need to challenge the homogeneity of the category 'women'. Studies must also include minority ethnic women and their perspectives and experiences.

This study aims to illuminate the operation of the 'race' dimensions of access (where South Asian women's healthcare experiences and perspectives are rooted in their experience of what it is to be constructed as racially different) and to examine the gender dimensions of access (where women's healthcare perspectives and experiences are grounded in their experience of gender difference) alongside cultural dimensions (based on women's world views). The interrelationship between factors such as gender bias and racism can make a stronger case for tackling them, than a situation where research has prioritised one factor as a catch-all explanation for inequalities in access to healthcare that may exist among minority ethnic groups.

As noted above, more work on minority ethnic groups and healthcare has focused on ideas about 'race' difference and health than on ideas about gender difference and health. This is reviewed below. Studies have tended to use 'race' to measure differences in health status, i.e. 'race' is taken as an explanatory variable rather than as a marker of differences which themselves require explanation. The effects of racism on access to healthcare clearly require more investigation. An access focus can assist an examination of the effects of racism on patterns of healthcare in three ways. Firstly, it can help to document differences in treatment between people. Secondly, it can help us to understand South Asian women's experiences of, and perspectives on, racism in healthcare. Finally, it can help us to move beyond the documentation of discrimination to an understanding of how this type of

discrimination and exclusion works, occurs and persists (e.g. Anthias and Yuval-Davis, 1993; Gelsthorpe, 1993). It is necessary to identify racism, and not to use racism to explain all the healthcare experiences of minority ethnic groups (Bowes and Domokos, 1995a) if we are to understand the way racism operates and if racism is to be challenged.

Racism is a complex phenomenon and occurs in different contexts. This means that the accounts of those who experience racism are vital in understanding racist processes. Racism in the health service is not new and has been the subject of much concern (e.g. Ahmad, 1993a; Ward, 1993; Mama, 1992; Cox and Bostock, 1989; Pearson, 1989; Baxter and Baxter, 1988; Kushnick, 1988; Fenton, 1987; Rathwell and Phillips, 1986; Doyal, 1985b). However, much of this work has been at a policy or theoretical level rather than at an empirical level. Other authors, for example Bryan *et al.* (1985), are more specific about the need for further work on the experience of racism among health service users. In the light of my discussion above, I would argue that there is also a need for more work on the effects of racism on healthcare in its broadest sense. A conceptualisation of access that includes South Asian women's experience of and perspectives on healthcare is therefore relevant. As a number of commentators have argued (e.g. Stubbs, 1993) racism is more than just a variable to be measured empirically, it is also felt and challenged by those who experience it.

Racism, in its broadest sense may be defined as 'prejudice based on purported racial identity' (Bowes and Domokos, 1995a: 37). It is not fixed but is changing and dynamic; long-standing and evolving (Stubbs, 1993) and draws on a reservoir of racist images and stereotypes (Jackson, 1989). Racism operates at all levels of society and takes a number of complex forms. Indeed, some commentators prefer to refer to 'racisms' (Solomos and Back, 1994; Stubbs, 1993; Brah, 1992) drawing attention towards the entrenchment of racism in society, and to the different interconnecting levels at which racism operates and changes over time. This analysis shows that racism may be indirect or direct, subconscious or conscious and that the different levels of racism are interlinked. For example, racism keeps minority ethnic groups in low status in terms of health or education or housing (institutional). In doing so this confirms/legitimises ideas about minority ethnic inferiority (structural) that permeate into common-sense (interpersonal) (Ahmad, 1993a).

At the interpersonal level, racism can operate firstly, through overt racial prejudice and discrimination by individuals. Studies have argued that racial harassment or hostility has a number of effects on health (Smaje, 1995; Howlett *et al.*, 1992; Pearson, 1989). Secondly,

interpersonal racism can operate through stereotyped assumptions that might be made by health professionals. According to Ginsberg (1992) stereotyping is a way of handling the common-sense racism in society in an everyday context. There is a small body of work which reports that health professionals hold, interpret and deal with problems by using negative stereotypes of South Asian patients, and that this has implications for provision and the quality of healthcare as well as for individual healthcare choices (e.g. Bowler, 1993a, 1993b; Patel, 1993; Ahmad *et al.*, 1991a; Evers *et al.*, 1989; Kushnick, 1988).

At the institutional level, racism is institutionalised in the routine structures and practices of institutions. Writers on minority ethnic groups have argued that the structures of healthcare and state welfare discriminate against minority ethnic communities (Ahmad, 1993a; Mama, 1992). A number of authors have identified barriers to service access resulting from ethnocentric and racist provision (McNaught, 1988; Donovan, 1984; Brent CHC, 1981). They show that access is compromised where health service provision is ethnocentric, where the cultures and identities of groups become devalued and where minority ethnic groups are excluded from influencing routine practices and procedures. Institutional racism means that racist practices may be routine, 'normal' and 'subconscious'. These processes are not fully explained by interpersonal racism among the staff of institutions but may be legitimised by stereotypes of minority ethnic clients (Ginsberg, 1992).

Structural racism, according to Ginsberg (1992), links racism to the outside society and to the policy environment that mediates access to services. Structural racism helps to conceptualise ways in which racism operates at a level that is not tangibly institutionalised in health services. It shows that racism in health services is linked to racism in other sectors of political economies. Williams F. (1989) argues that structural racism has been pervasive in the NHS. Minority ethnic groups have been defined ideologically as 'a problem', 'a threat' or a burden on resources and as service abusers who have no legitimate claim on goods or services. She argues that this means that the benefits of the NHS have historically not been extended to 'immigrant' populations and that minority ethnic groups are not seen as under-served, the dominant racist construction is that they are 'undeserving'. Clearly this affects access to healthcare in its broadest sense.

Finally, new forms of racism are relevant to a study on access to healthcare for minority ethnic groups. Contemporary manifestations of racism occur where 'race' is coded as culture (Solomos and Back, 1994). The reification of minority ethnic culture means that the

qualities of minority ethnic culture become the central unit of analysis in research and that culture becomes 'natural' and 'fixed'. Culture then becomes coded in a language that circumvents accusations of racism. I have argued above that explanations of minority ethnic groups and healthcare that draw on constructions of minority ethnic culture limit an understanding of the effects of structural factors on access to healthcare. Such contemporary manifestations of racism can have racist effects whilst denying that the effect is the result of racism (Solomos and Back, 1994) and attention is deflected from the structures of oppression (Black Health Workers and Patients Group, 1983). In effect, systematic racism becomes reduced to cultural misunderstandings and is depoliticised.

In a study on South Asian women's access to healthcare it is important to be alert to the possible use of culture as a euphemism for reproducing ideas about racism. I have argued above, that much work on minority ethnic groups and access to healthcare has overemphasised constructions of minority ethnic culture and this has contributed to the construction of minority ethnic groups' health needs, problems and solutions to them. In addition, it may be said that the culturalization or ethnicization of 'race' difference in access to healthcare is perhaps more ingrained in healthcare than other areas of public policy and provision. For example, Ahmad (1993b) and Stubbs (1993) argue that other areas of public provision such as social work and education have long since engaged with debates about the relevance of 'culture' against 'racism', multiculturalism and anti-racism and 'black perspectives' in policy and practice. The challenge to racism and to sexism, however, has been less 'progressive' in health services.

Section 1.4.1 described past disease centred research on minority ethnic groups. Sheldon and Parker (1992a, 1992b) and Douglas (1992) highlight some of the dangers of using 'race' or ethnicity as an explanatory variable and the effects of definitions of ethnicity used mainly in epidemiological research. Their criticism centres on the use of ethnicity as a variable which is uncontextualised and thereby becomes an objective fact rather than a socially constructed category. They show how ethnicity is made to become the cause of a number of health problems, side-stepping a number of other issues, instead of prompting a wider assessment of causes of health problems. Sheldon and Parker (1992b) suggest that ethnic categorisation may be responsible for the construction of some ethnic differences in health. They criticise research that naturalises ethnic boundaries or that correlates ethnicity with other factors in a supposedly meaningful and objectively scientific way. They argue that

this justifies the neglect of the effects of structural factors on health inequalities and experience, and diverts attention from the process of providing care and access issues.

As noted above, my study aims to highlight the 'race', gender and cultural dimensions of South Asian women's access to healthcare. This will help to challenge a literature on minority ethnic groups and healthcare which is generally gender blind and a literature on women's health and healthcare which is generally 'race' blind. In order to make progress in understandings of access to healthcare for minority ethnic women, research needs to be more open to understanding the shared dimensions of healthcare experiences and access to healthcare, as well as the differences in health experiences between social groups. A broader conceptualisation of access to healthcare is therefore relevant. The only way to achieve this is to understand the experiences and perspectives of minority ethnic groups themselves. It is hoped that this study will give a detailed understanding of access to healthcare which is sensitive to the experiences and perspectives of South Asian women.

In the light of the debates outlined above, the next section considers health policy in a number of areas relevant to South Asian women's healthcare. It highlights the influence of culturally deterministic arguments on, and the invisibility of minority ethnic women's experiences and perspectives in, health policy. I then highlight the paucity of research in this field in Scotland, before considering my three chosen healthcare arenas.

1.5 The Official Response - South Asian women and health policy

A range of policies have sought to address inequalities in access to healthcare and have had implications for minority ethnic women as service users. In this section I discuss health policy selectively at a number of levels: health policy directed at women generally, at minority ethnic women and at minority ethnic groups. The invisibility of minority ethnic women's own perceptions and experiences is reflected in these areas.

Women and health policy

The literature on women's health policy overall is patchy, however, there are several areas of health policy which have explicitly targeted women. I will argue that the health needs of women have been constructed in particular ways and have centred on reproductive health. It is acknowledged that advances in healthcare provision have brought improvements for women such as access to safer childbirth or more reliable contraceptive methods, however,

assumptions behind welfare policies have paid less attention to the broader aspects of women's lives. This has limited their ability to tackle inequalities in access to healthcare. In particular, health policy has emphasised the medical model of health to the exclusion of social needs. I will draw on selected examples to argue that policy and provision has supported some but not all women's healthcare needs. Women have, therefore, both gained and lost as a result of policy and provision for women's health.

Studies show that women's use of healthcare provision is higher than men's. This is true for use of the GP service, psychological services, geriatric and preventative services (Doyal and Elston, 1991). There are many reasons for the greater use of health services by women: for most women their reproductive capacity brings them into contact with services in a variety of ways, in pregnancy and birth and for fertility control; they are more likely than men to be checked for the reproductive implications of ill health; they are targeted in health policy that supports regular checks such as cervical cytology; and women may act as negotiators of healthcare for others, where they are deemed responsible for the care of their children and their families. Their use of healthcare provision may also be higher due to gender differences in attitudes toward ill health and help seeking behaviour (Doyal and Elston, 1991). Additionally, women generally live longer than men and in old age they are likely to experience more chronic ill health.

Despite women's broad use of services, policy targeting women has focused on reproductive issues. Women's health needs then have been defined primarily in relation to reproductive functions. Craddock and Reid (1993) describe changes in health provision for women. For a long time provision focused on maternity care. Through the 1960s and 1970s it focused on reproductive health and the provision of reproductive and family planning clinics. Such clinics were free and run on a sessional basis for married women only until the 1970s. Cervical cytology provision was bound up with the stress on reproductive health. It was offered in cytology clinics alongside services such as blood pressure estimation. Cervical cytology is an early example of how women's health problems have been defined in terms of the treatment of particular conditions to the neglect of women's health in a more holistic sense.

Policies relating to women's fertility control emphasise the role of women as child bearers and reflect an ideology of a 'natural' obligation to motherhood. According to Doyal and Elston (1991) they are formulated in the context of a wider set of ideas about women and

their place in society and are part of the means by which gender divisions are maintained and reproduced. Debates in the literature addressing policy targeted at women have centred around contraception and abortion. Doyal and Elston (1991) present a historical account of both types of provision in Britain. They note only gradual intervention in the processes of pregnancy. In Victorian times the provision of contraceptive advice was a public offence and it was not until 1976 that fertility control services were fully integrated into the NHS. Similarly abortion changed from being an offence to being legalised under the 1967 Abortion Act. However, whilst the legalisation of abortion passed it into medical control this was not matched by extra NHS resources. In addition, over the 1970s and 1980s abortion reform was threatened by certain attempts to restrict its scope (Williams F., 1993). In recent years a large proportion of provision has come from the charity and voluntary sector and many abortions are performed in the private sector (Oakley, 1983). Oakley's (1983) evaluation of abortion policy argues that policies can have three aims: to increase the personal freedom of women, to improve the nation's health or to control population trends. She argues that both pro and anti-abortionist policies emphasise the latter two aims over the former.

Health policy targeted at women emphasises the dominance of the medical model of health to the exclusion of social needs. Well women clinics provide a good example through which to study this. These clinics developed from cytology clinics and provide a wider package of services for women. More recently well women clinics have offered broader services such as advice on weight and smoking. This is in accordance with the Patient's Charter (DoH, 1991) which stipulated that GPs have to make provision for health education. However, the emphasis is still on contraception and screening (Craddock and Reid, 1993).

Well women clinics brought an alternative model of healthcare for women. They tried to avoid the identification of healthy women as sick patients and to place an emphasis on the whole woman. Their development is linked to the women's health movement in Britain and the US in the 1960s and 1970s which evaluated health provision for women and its impact on health and welfare. The women's health movement aimed to eliminate sexism in medical practice, to assert claims to knowledge over women's bodies and to challenge medical control over reproduction (Pascall, 1986). It also challenged the benefits gained from caring services provided for women by the welfare state (Foster, 1991).

The dominant approach to well women provision emphasises a medical model rather than a social model of provision. This medical model of provision focuses on medical solutions to medical problems. It is 'doctor centred', oriented to physical health and health problems are defined by the medical profession. In contrast, the social model broadens the definition of women's health by emphasising holistic healthcare including psychological and emotional needs, the issue of control over women's own healthcare and non-medical treatment for clinical problems as well as preventative health initiatives (Craddock and Reid, 1993; Foster, 1991). In practice well women clinics may suffer from underfunding (Craddock and Reid, 1993). They may include NHS funded health professionals with additional services, such as counselling, self-help groups and health education, provided by other health workers and volunteers. The latter social health needs may be marginalised. As a result this type of woman oriented care has grown up on the boundary of mainstream provision.

A stress on the role of women as child bearers and the stress on the medical model neglects other gender differences in health experience and healthcare needs. For example, it neglects women who are past or passing their reproductive years (Pascall, 1986). As noted above women feature strongly among older people with chronic health problems, among the physically handicapped and those treated for mental health problems. Pascall (1986) also notes the low priority given to women's handicapping ill health such as rheumatism or arthritis, or to orthopaedic work.

Policy makers have also excluded the social needs of women and have failed to link health to social and environmental aspects of women's lives. Policy has failed to adequately tackle structural issues that reinforce ideas about gender difference and affect women's health and well-being and access to healthcare.

Critics challenge the narrow notions of health and healthcare in health policy which have been concerned solely with women's biological characteristics. These notions fail to connect individual health and access to healthcare to socio-economic constraints and the social and economic roles of women. Critics challenge the lack of emphasis on the private sphere in policies affecting women and the lack of support for women as healthcare producers. It must be remembered that healthcare provision extends beyond the immediate decisions of treatment and diagnosis (Doyal and Elston, 1991) and that health professionals make judgements about a range of issues beyond the clinical domain. Critics stress the absence of policy and state support for women in caring activities (Foster, 1995). Women

provide a reservoir of care for those not deemed to be the responsibility of the NHS (Doyal and Elston, 1991), both in terms of caring for the sick and the disabled and in maintaining family health through domestic labour (Doyal, 1991). Critics also highlight the lack of comprehensive policy targeting out of home childcare, nursery provision and maternity grants. According to Oakley (1983) policy and provision in these areas would have a positive effect on women's health. This leads Foster (1995) to argue that women's health could be improved by spending less on medical interventions and more in other areas of policy and provision.

Minority ethnic women and health policy

Health policy has also defined minority ethnic women in particular ways. This has implications for addressing inequalities in access to healthcare for minority ethnic groups. Some elements of the debates are similar to those in my discussion of policies targeted at women generally, but others take a particular form.

Both the literature on health policy targeting women and minority ethnic women focus on women's role as child bearers. The Asian Mother and Baby Campaign (AMBC) illustrates the construction of minority ethnic women's health needs through policy. It was the most extensive health education campaign directed at South Asian women in Britain, ran from 1984-1987 and was implemented in 16 Health Districts. The AMBC comprised a publicity campaign encouraging earlier booking for ante-natal care and a linkworker scheme between women and health professionals throughout pregnancy, delivery and six weeks after birth. This aimed to increase women's awareness of service availability, and their uptake of services (Rocheron and Dickinson, 1990).

In common with health policy targeting women more generally (Foster, 1995; Oakley, 1983), critics argue that minority ethnic women's health needs and policy responses do not necessarily coincide. They question the contribution of such campaigns in improving minority ethnic groups' access to healthcare. One of the major criticisms of the AMBC was that it did not do enough to consult women or to help them to make informed healthcare choices and so was out of line with their desires (Parsons *et al.*, 1993; Rocheron and Dickinson, 1990). Another criticism was that the onus for change was placed primarily on women and secondarily on health professionals. Foster (1995) argues that women's healthcare in the NHS is determined largely by the providers of healthcare rather than the

needs of women. This is bound up with the NHS as a major employer, the status of the medical professions, technology and the pharmaceutical and medical industries.

Some debates in women's health policy take a particular form for minority ethnic women. As argued above, whereas one of the central debates on fertility in women's health more generally focuses on abortion, the literature on minority ethnic women's health stresses issues of their right to fertility. Black feminist authors have highlighted that minority ethnic women experience issues of fertility control in different ways compared to majority ethnic women (Williams F., 1993). Abortion, sterilisation, hysterectomy and injectable contraceptives are highlighted as controls used by state professionals to control the fertility of minority ethnic groups (Douglas, 1996; Mama, 1992; Bryan *et al.*, 1985). Mama's (1992) work shows how health services have participated in the monitoring and regulation of minority ethnic groups in the UK. This illustrates the invisibility of minority ethnic women's health needs, experiences and perspectives in the literature on women's health policy and provision. This invisibility is reinforced in health policies that have targeted minority ethnic groups.

Minority ethnic groups and health policy

Health policy has also targeted minority ethnic groups. Over the years policy responses to the healthcare needs of minority ethnic groups have been and continue to be patchy at best. Different approaches have been made at different times and in different places. Social policies relating to minority ethnic groups have adopted a range of perspectives and models moving from models of assimilation, to integration, to multiculturalism to anti-racist practice. These approaches cannot be divorced from the dominant ideologies and social policies relating to 'race' and the presence of minority ethnic groups in Britain (Douglas, 1995). A number of approaches addressing aspects of health are discussed below. Like the other areas of health policy discussed above, all have strengths and weaknesses.

Until recently, welfare policy worked with a limited view of social inequalities and divisions. During the period 1950 to 1980 most studies used categories defined by welfare professionals such as 'problem families' or 'the handicapped'. This made people into 'passive recipients' of welfare. In the main, policy did not reflect other social divisions such as gender and 'race' difference (Williams F., 1993). Since then, some policies have been geared towards the specific needs of minority ethnic groups. However, policies specifically designed to meet the health needs of minority ethnic groups as defined by them or based in

their experiences are relatively recent. According to Bahl (1993), it was not until the 1980s that policy started to be planned in a 'sensitive' manner and, as Douglas (1995) notes, anti-racist approaches emerging from within minority ethnic communities have never been fully sanctioned in health policy.

Many official responses to minority ethnic groups and health have been based on predefined issues and assumptions about minority ethnic groups and inequalities in access to healthcare. Health policy has, therefore, been instrumental in reconstructing the reality of minority ethnic groups' healthcare needs. Again this does little to address or to 'include' the perspectives and experiences of minority ethnic groups or to address structural issues affecting their access to healthcare.

In parallel with a number of research foci described above, policy targeting minority ethnic groups has been preoccupied with what is 'different' about minority cultures and diseases. Provision has tended to focus on 'the exotic', 'the specialist' and what might be termed 'the peripheral'. It has also focused on cultural deficiencies and has sought to single them out and to change them. It has ignored and failed to support the healthy behaviours and healthy cultural practices including lower rates of smoking (Health Education Authority, 1994; Dickinson and Bhatt, 1994) and lower alcohol consumption among South Asian women compared to the majority ethnic population.

The earliest initiatives did not address inequalities in health and access to healthcare but focused on issues seen as potential threats to the British population (Pearson, 1986b). In line with assimilationist perspectives of the early 1960s, it was not considered necessary for society to make any adaptations to a changing population. Institutions were felt to be adequately accessible and any difficulties encountered were considered to be the result of the shortcomings of minority ethnic groups. Johnson (1993a) describes the earliest responses of health services to minority ethnic groups themselves. He outlines the spread of 'port medicine' to eradicate imported diseases, such as sexually transmitted diseases and tuberculosis, to protect the majority ethnic population whilst minority ethnic groups took on a 'British' way of life and became assimilated into dominant white cultures (Douglas, 1995).

During the mid to late 1960s models of social integration deemed that minority ethnic groups should not totally abandon their culture. Social policies emphasised the recognition of cultural differences and 'tolerance' (Douglas, 1995). This spawned literature on the cultures and lifestyles of minority ethnic groups (e.g. Henley, 1979). Further, the use of

culture in explanations of minority ethnic groups' healthcare experiences became the focus in social policy which moved away from integration toward multiculturalism.

The overemphasis on constructions of culture and the racialised construction of health needs has resulted in a number of healthcare initiatives targeting South Asians. Since their implementation, studies have questioned whether such campaigns reflected the priorities of minority ethnic groups themselves and so have questioned their impact on access to healthcare. Health education campaigns targeting minority ethnic groups, for example the 'Stop Rickets Campaign' and the 'Asian Mother and Baby Campaign' (described above) have received detailed criticism from the groups which they purported to help as well as from academics (Douglas, 1995; Rocheron *et al.*, 1990; Mason, 1990; Rocheron, 1988). Less high profile campaigns against *surma* have also been targeted. These have been deeply criticised by Pearson (1986b) as culturally racist as they focus on minority ethnic groups' problems without reflecting on the effects of racism in structuring health experience.

The racialisation of health problems is illustrated in the Stop Rickets Campaign (1981). Targeted specifically at South Asians, it pinpointed culturally inappropriate and other 'internally' generated practices and linked these to the incidence of disease. The incidence of rickets was attributed to genetic deficiency, to Asian diets, maladaptation to the British climate and to a South Asian lifestyle which stopped women and children exposing their skin to sunlight (Pearson, 1986b). Responses failed to link rickets to wider inequalities and poverty in the same way as policy had previously done for the majority ethnic population (see also section 1.4.1).

Policy responses urged South Asian populations to adopt British practices and lifestyles, for example, a British diet in order to improve health. They alerted professionals to give advice on vitamin D and highlighted the need to overcome language and cultural barriers at the point of delivery. This stance was quite different from the action taken to combat rickets in the majority ethnic population during WW2 which had led to the fortification of particular foods, for example, margarine and the availability of free milk to children. The reasons for not fortifying other foods, such as chapatti flour, in the same way remain unclear (Pearson, 1986b). The incidence of what was then termed 'Asian rickets' along with a range of 'exotic' diseases was seen to be 'imported' rather than linked to an analysis of life experience, socio-economic and environmental factors in Britain (Smith, 1989; Rocheron, 1988).

The Stop Rickets Campaign had much in common with the AMBC. Both set out community based health education programmes and advised on lifestyles and the use of health services. Both had at the root of the problem minority ethnic groups' limited knowledge of health issues. Both policies focused on language and cultural barriers at the point of service delivery, and aimed to change individual health behaviour toward majority ethnic norms (Smaje, 1995). The unspoken assumption was that it was 'their intransigence' that was to blame (Pearson, 1986b: 50). In many respects these campaigns were short sighted and damaging and were implemented without proper consultation with members of the groups themselves. Local South Asian organisations were only involved at a later stage (Pearson, 1986b). I would argue that policy targeting the needs of minority ethnic groups needs to be informed by the perspectives and experiences of minority ethnic groups themselves. Such campaigns encouraged minority ethnic groups to be 'passive' recipients of healthcare, not active in their own health and ignored minority ethnic groups' struggles and modes of resistance in the UK. All these factors compromise the ability of health policies to tackle inequalities in health and access to healthcare for minority ethnic groups.

Mainstream initiatives

An analysis of policy initiatives affecting minority ethnic groups shows that minority ethnic concerns remain largely separate. 'Race' difference has been considered in isolation from other policy concerns. This has led to a tendency to create 'special' policies on 'race' issues rather than a tendency to consider the implications of all policies for minority ethnic groups (Ahmad, 1993b) or to consider the needs of minority ethnic groups in mainstream care. This may be because special needs are considered to be less threatening and more easily accepted and implemented. Below I examine mainstream policy responses which aim to enhance minority ethnic groups' access to healthcare. These can be grouped under two headings: policy has either been colour blind or to a limited extent ethnically sensitive. Overall, minority ethnic groups and their realities suffer from a lack of inclusion in mainstream policy and there is little co-ordination in service responses that affect minority ethnic groups.

Colour blind practice works by 'treating everyone the same' so that equal provision is made for all, irrespective of ideas about 'race' difference or colour. Critics have argued that a false sense of universalism compounds the invisibility of minority ethnic groups (Johnson 1993a; Pearson 1989) and may in itself be racially discriminatory (Phoenix, 1990). Colour-

blindness denies the specific experiences and needs of minority ethnic groups and fails to recognise disadvantage in healthcare or the everyday experiences of minority ethnic groups (Pearson, 1989). In service delivery this means that planning may be informed 'only by myth and prejudice' (Johnson, 1993a: 191). As a result, there is seemingly little need to target resources in mainstream care at South Asians for example, or to improve access in other ways, for example, taking steps to alter inaccessible services.

Studies show that inequalities in access to healthcare may be compounded where universal provision has ignored the particular health needs of minority ethnic groups whilst supporting provision relating more to the needs of the majority ethnic population. For example, minority ethnic women may not necessarily be given specific treatment when it is needed. Johnson (1992) and Phoenix (1990) compare responses taken to screen babies for phenylketonuria with responses to screen for sickle cell anaemia and beta-thalassaemia. Phenylketonuria affects virtually only white children and has a very low incidence about 1 in every 100,000 births (Prashar *et al.*, 1985). It is routinely screened for soon after birth. In contrast 1 in 200 babies of Afro-Caribbean origin and 1 in 100 babies of West African origin are born with sickle cell disease (Prashar *et al.*, 1985). Beta-thalassaemia especially affects those with heritage in the Mediterranean, South East Asia and in the Indian subcontinent (Phoenix, 1990). Both diseases are potentially life threatening if untreated, though the effects of beta-thalassaemia cannot be avoided even with early treatment. All pregnant Afro-Caribbean women are routinely screened for sickle cell disorders in case they need anaesthetics and if a woman has a trait then her partner may be screened. It is also now possible to make a diagnosis on the fetus. Despite the high incidence of the disease and ease of diagnosis, there is no blanket policy to cover general screening, counselling or an adequate information base. This has occurred despite being a focus for epidemiological research along with long term campaigning and voluntary sector responses (Anionwu, 1993).

A second type of policy response (enacted as a consequence of the failure of universalism) has moved toward ethnic sensitivity and has focused on issues of difference that exist in the UK population. However, in practice, as with colour-blind policy, this does little to consider the attributes of health services, structural dimensions of access or the position of minority ethnic groups in the NHS. According to Stubbs (1993) many responses have entailed a better understanding of the customs, traditions and religious activities of minority ethnic groups. The main implication of this type of ethnically sensitive approach is that

access problems are internally generated. What we now appreciate is that ethnic sensitivity is not just a question of language or culture for example. It involves support for variations among different people, the continual awareness of need and a process of constant improvement (Bowes and Domokos, 1995a). This means that the attributes of health services, not just the attributes of service users need to be examined.

Some authors give cause for concern and question whether ethnic sensitivity is achievable. The provision of ethnically sensitive services is often seen to be at odds with the interests of majority ethnic users. This has resulted in a lack of consideration being paid to the needs of minority ethnic groups in planning mainstream services. Despite the campaigning of minority ethnic groups against unfavourable healthcare provision, a number of authors note the unwillingness of health professionals and policy makers to move toward truly ethnically sensitive provision (Bowler, 1993a; Ahmad *et al.*, 1991b). Some have questioned the level of commitment to change by the medical establishment (Parsons *et al.*, 1993; Stubbs, 1993; Johnson, 1992). The lack of response to a changing population by health services was highlighted by the National Association of Health Authorities of England and Wales in the 1980s (NAHA, 1988). More recently, Ahmad (1994) has noted little improvement.

Where difference in health experience between social groups has been acknowledged little attempt has been made to address problems. I illustrate this point by examining two types of response. Firstly, at the governmental level 'The Health of the Nation' (DoH, 1992) noted a lack of information about ethnicity and health. This was the first time the government had formally acknowledged that the health and disease experience of minority ethnic groups may differ from that of the general population (DoH, 1993). Despite highlighting differences in illness prevalence and morbidity rates among ethnic groups, it failed to outline initiatives to tackle issues. Good practice was not included in its key aims and targets. In addition, it paid little attention to the quality of healthcare provision and has since been criticised as being colour-blind (Johnson, 1992). Secondly, the health inequality debate has been 'under racialised' (Stubbs, 1993). It has ignored minority ethnic groups' specific positioning in patterns of health inequality, share of health inequalities in terms of health status and the differential impact of service provision on different ethnic groups. The famous Black Report (Townsend and Davidson, 1982) and the Health Divide (Whitehead, 1987) gave only tokenistic acknowledgement of 'race' difference and racism despite indicating both 'race' and gender differences in access to, and distribution of, resources and the quality of care.

In contrast, some authors see cause for optimism and potential challenges to the invisibility of minority ethnic groups in mainstream provision. A number of initiatives indicate that minority ethnic issues have taken on more importance. These include recent mainstream initiatives: the creation of the Ethnic Health Unit, set up in 1994 and funded for three years aims to monitor equity in provision and good practice, and support purchasers and providers of healthcare in improving access to health services for minority ethnic populations. Also the creation of Services for Health and Race Exchange (SHARE) funded by the Department of Health which aims to increase information in the area. Further, Johnson (1992) notes the increase in material portraying black perspectives and needs in forms accessible to policy makers and practitioners. This includes the Code of Practice in Maternity Care published by the Commission for Racial Equality (CRE, 1994), and the Checklist on Health and 'Race' published by the King's Fund (Gunaratnam, 1993). This is added to by the 1991 Census results which have revealed information on limiting long term illness among minority ethnic groups. Further initiatives include ethnic monitoring in the NHS, set up in 1994, focusing on in-patient care which since April 1995 has provided data to inform resource allocation and planning (Mihill, 1993). However, it must be stressed that ethnic monitoring and Census results only tell us about uptake rates of inpatient services or rates of ill health. They reveal little about minority ethnic groups' experience and perspectives on the healthcare received or about their own needs.

Further opportunities for 'consultation' with minority ethnic groups parallel new right initiatives which emphasise consumer choice and sovereignty. Johnson (1992) and Pearson (1989) see that changes in government orientation may urge greater attention to user views and lead to improvements in anti-discrimination measures. Examples of initiatives include The Patient's Charter (DoH, 1991), which provides an explicit expectation of equality and gives standards against which providers can be measured. Johnson (1992), however, urges that greater attention be paid to anti-discrimination measures. In addition, the White Paper 'Working for Patients' (1989) highlighted the need to define the health and social care needs of populations before purchasing healthcare. It also highlighted the need for services to be accountable. Johnson (1992) and Pearson (1989) argue that the increasing emphasis on consumer choice and views, accountability and acceptability of health services might give the opportunity to leave stereotypical views of minority ethnic groups' health needs behind.

This short and selective review has shown that health policy targeted at minority ethnic groups, minority ethnic women and women more generally, has some way to go to address

the needs and experiences of minority ethnic women in healthcare provision and perhaps a longer way to go than other arms of welfare provision. I have argued that health policy has defined women and minority ethnic women in particular ways and has centred on reproductive health. I have also argued that mainstream health policy has excluded racialised groups. Policies addressing women's health have not considered minority ethnic women and policy directed at minority ethnic groups has focused on the differences, rather than the similarities, between minority ethnic and majority ethnic groups. My discussion has also shown that culturally deterministic arguments have had a far reaching effect on health policy. Where policies based on special provision have predominated, a lack of consideration has been paid to the healthcare experiences and needs of minority ethnic groups in mainstream provision. In addition, my discussion has shown a lack of examination of the attributes of health services and racism and sexism in health service provision.

1.6 The Scottish South Asian community in Edinburgh and research on South Asian women's health in Scotland

Despite an increasing number of studies on minority ethnic women and healthcare, the invisibility of the experiences and perceptions of minority ethnic groups and minority ethnic women in health policy and health research is compounded in Scotland. This section makes the case for more work to be undertaken in Scotland on minority ethnic women's experiences and perceptions. My study contributes to the patchy but growing literature focusing on the Scottish experience.

For many years the health needs of minority ethnic groups have largely been ignored in Scotland. Little research into minority ethnic groups and health took place in Scotland until the 1980s. Previous studies South of the border tended to generalise findings from England and Wales to cover the UK or to provide a superficial analysis of 'race' questions in Scotland (Donaghy, 1994). According to Dunlop and Miles (1990: 145):

'...despite the reference in the titles of these to Britain, very little attention has been paid to Scotland. From even a cursory glance through the literature, one is immediately struck by the historical invisibility of people of South Asian and Caribbean origin in Scotland.'

It is, however, important to ascertain the distinctive features of, and similarities in, the experience of minority ethnic groups in Scotland (Bowes and Sim, 1991). In part, the relative lack of research has been 'excused' by the small size of the population. The 1991

Census shows that the total minority ethnic population makes up approximately 1.3% of Scotland's population, with concentrations in Glasgow and Edinburgh and a smaller concentration in Dundee. However, Scotland has a different migration history, a different composition of minority ethnic groups and a different ideology about migrants compared to England and Wales (Miles and Muirhead, 1986).

There has been some research on minority ethnic groups and health in Scotland. In general it falls into three categories: that focusing on specific issues and diseases; on health status; and on service uptake. The literature shows that until relatively recently, little work in Scotland has focused on South Asian women's experiences and perceptions of health and healthcare, with the notable exceptions of in-depth work by Bowes and Domokos (1995c, 1993) and Donaghy (1994) and work on health needs assessment by Bhatnagar and Ineson (1994).

Studies which include South Asian women have focused on specific issues. Examples include work on remedies and traditional medicine (Bhopal, 1986a), and a range of preventive health issues such as smoking, alcohol and heart disease (Sheikh and Jiwa, 1993; Bhopal, 1986b). Little research has been designed to examine healthcare issues as women themselves define them.

There have been an increasing number of studies centring on service use. For example, McFarland, Dalton and Walsh (1987) on the use of social and welfare services and Pershad and Tyrell (1995) on minority ethnic women and maternity services in East Pollokshields. However, more studies need to address access to primary healthcare.

Despite increasing evidence of poor health status among minority groups in Scotland few studies consider general health and healthcare in ways which illuminate the healthcare experiences of minority ethnic groups. This occurs despite evidence that points towards differences in the health profiles of South Asian men and women. For example, the Glasgow based Twenty-07 study shows that among the South Asian population, women's health is worse than men's. Also the health gap between South Asian women and men is greater than that between women and men in the majority ethnic population (Williams R., 1993; Williams R. *et al.*, 1993).

Finally, although there has been increasing recognition of the structural experiences of minority ethnic groups in Scotland, few studies have examined the effects of structural

factors on access to healthcare and health issues. This has taken place despite a number of studies which have challenged the understanding that there are no 'race' relations problems in Scotland (Young, 1993; Armstrong, 1989). A survey by the Scottish Council for Racial Equality in 1988 showed that 80% of Pakistanis and Indians had experienced racist abuse with 60% of Indians registering physical attack (Tyler, 1988). In addition, local surveys have highlighted the significance of racism in other arms of welfare provision such as housing and social services (McCluskey, 1991; Bowes, McCluskey and Sim, 1990a, 1990b; Dalton and Daghlia, 1989; McFarland *et al.*, 1987). However, the only national survey to date on minority ethnic groups (Smith, 1991), which included some findings on health service provision and carers, stated explicitly that it did not aim to uncover ideas about unequal treatment on the basis of 'race' difference.

This section has shown that more work is required if we are adequately to document the experiences and perceptions of minority ethnic groups in Scotland, in particular South Asian women. My argument is that we need to consider the health perceptions and experiences of South Asian women in order to understand the problem of access to healthcare in its broadest sense. The next section outlines the three healthcare arenas I have chosen in order to illustrate this point.

1.7 Setting the Research Frame

This section sets out my research frame in the light of debates on access to healthcare and on the effects of 'race', gender and culture found in the literature on minority ethnic groups and healthcare. It is hoped that the areas focused on will help to conceptualise and refine questions around access and suggest areas for further study.

1.7.1 The Three Healthcare Arenas

I have argued that access to healthcare is more than just the use of health services. Healthcare is negotiated in a number of arenas or environments. It is everyday, episodic and periodic. This means that understandings of access to healthcare need to consider a number of healthcare arenas. I have chosen to focus on three specific healthcare arenas. These are 'everyday' healthcare outside health services, the General Practitioner service and cervical cytology screening (i.e. informal care, general mainstream health servicing and targeted preventative screening services). Each arena enables me to consider different dimensions of

the bigger picture of South Asian women and access to healthcare and to examine the interrelationships between ideas about 'race' and gender difference and culture. In order to highlight issues each empirical chapter is structured in the same way. Firstly, I consider the constraints and enablements on access to healthcare at the individual level, focusing on the actions, experiences and key concerns of individuals. Secondly, my analysis broadens to consider access at the collective level and the factors that are beyond the control of the individual and affect everyone in similar circumstances, thus setting access issues in the collective social environment. I use women's perspectives on and experiences of healthcare to interpret which factors affecting access can be attributed to ideas about 'race' and gender difference.

Chapter 3 examines access to healthcare for South Asian women outside health services. By healthcare outside services I mean everyday healthcare practices that do not directly involve formal service use. This healthcare arena contributes to an understanding of access to healthcare in a number of ways.

It adds to an understanding of South Asian women's healthcare. Cultural dimensions of access have been stressed in understandings of minority ethnic groups and access to healthcare outside health services. Understandings of this healthcare arena have been plagued with stereotypes and culturally deterministic research. As noted above, the health behaviours and attitudes of South Asian women have been pathologised and culture is seen to be 'bad' for health. This means that few studies have highlighted minority ethnic women's own concerns, attitudes and actions or the 'race' and gender dimensions of access that might also be relevant to South Asian women's experiences in this healthcare arena. My study aims to pinpoint the concerns and experiences of South Asian women and to use their world views to challenge some of the stereotypes of South Asian women's health concerns and their pathological health behaviours.

A broader conceptualisation of access urges us to widen our notion of healthcare to include 'everyday' healthcare outside services. Chapter 3 argues that healthcare is not only for women, it is also given by them. A focus on healthcare outside services challenges the invisibility of this healthcare arena in understandings of access to healthcare which have centred on the uptake of, and the physical distance to, health services. My argument is that healthcare is as much a matter for the individual as for the health professional, in terms of diagnosis, treatment and health maintenance. Indeed not all people who are ill or

experiencing distress or disability use services and most health maintenance takes place outside services. The extent of this need and the ideas of users about the management of health may not be known to providers. This chapter is split into two sections, South Asian women's attitudes to health and ill health and their healthcare actions - health maintenance and coping with ill health.

A focus on access to healthcare outside services also challenges a number of debates in the literature on minority ethnic groups and healthcare. Firstly, it allows a consideration of similarities in the health experiences of South Asian women and majority ethnic women in the literature. As argued above, culturally deterministic research has centred on the differences rather than the similarities in health experience. Secondly, it challenges a focus on specific and 'different' diseases in the literature on minority ethnic groups and health. Thirdly, it moves away from measurements of health and the incidence of particular conditions toward healthcare actions and the means of coping with ill health and maintaining health. I have shown that culturally deterministic research has identified a number of key issues in the healthcare of minority ethnic groups, in particular specific diseases. I have argued that this has done little to uncover the views, experiences and realities of minority ethnic groups themselves or their own priorities and concerns.

Finally, a focus on access to healthcare outside health services adds to a number of debates in the literature on women's health. It helps to challenge the invisibility of minority ethnic women and their healthcare experiences and perspectives. It also helps to challenge the devaluation of women's healthcare experiences. Studies show that the overwhelming amount of care outside health services is done by women, including the health maintenance of domestic labour (Doyal and Elston, 1991). The gender dimensions of care in families, for example, are immediately relevant. However, studies also show that medicine has questioned the validity of other forms of healthcare besides health service provision and that women's own patterns of healthcare and their interpretations of their health experiences are often devalued (Roberts, 1985). Chapter 3 examines how women manage their health. It emphasises that women are able to judge, and are the best sources of information about, their own health and healthcare. It aims to tap women's own expertise about women's health (Roberts, 1992).

Health service users interact with health services in a variety of different health service settings for a number of different reasons. Douglas (1992) notes, that although there is a

growing literature on the health experiences of minority ethnic women, studies have concentrated on women's experience of maternity services (Woolett *et al.*, 1995; Hennings, 1993; Curren, 1986; Larbie, 1985; Clarke and Clayton, 1983; Lumb *et al.*, 1981; Homans, 1980). I have also shown that health services and their relationship with minority ethnic users remains under-researched in Scotland. Chapters 4 and 5 consider healthcare in two different primary healthcare arenas. Chapter 4 focuses on access to the GP service, a curative healthcare service which is used for a variety of reasons and chapter 5 focuses on access to cervical cytology, a specific preventative healthcare entitlement.

Both chapters examine the attributes of health services from the point of view of the user. Both arenas add to understandings of minority ethnic groups' access to health services. They aim to move away from explanations of access which draw on the issue of non-fluency in English as a catch-all explanation for the constraints on access to healthcare experienced by South Asian women. The chapters add to the dearth of studies focusing on South Asian women as users of health services and on the use of primary healthcare by minority ethnic groups (Ahmad *et al.*, 1989a).

Chapter 4 presents the findings on South Asian women's access to the GP service i.e. the services provided by the General Practitioner. The GP service is an example of a service where universal access is assumed for all. In addition, the GP service is a route to other forms of healthcare. It is a first point of entry into the health service and is therefore linked to my first healthcare arena. Also the GP service acts as a gatekeeper controlling access to other primary and secondary services as well as other sources of care.

A focus on South Asian women's experiences and perceptions of the GP service contributes to a number of debates in the literature on minority ethnic groups and healthcare. Explanations of patterns of use of the GP service have centred around constructions of South Asian culture. This leaves gender and 'race' dimensions of access submerged.

The literature reveals a number of assumptions about the patterns, and nature of, GP use among South Asian groups. Firstly, patterns of GP use have been pathologised. Studies on GP attitudes to Asian and non-Asian patients show that GPs perceive that Asians use the GP service too much compared to non-Asians (Ahmad *et al.*, 1991a, 1991b, 1989b; Wright, 1983). Secondly, the nature of GP consultation has also been pathologised. These studies also show that GPs assume that South Asians use the GP service more for trivial matters compared to non-Asians. A broader conceptualisation of access which includes South Asian

women's healthcare perspectives and experiences will help us to examine the key issues and health concerns of women as they see them, and to challenge the pathologisation of South Asian women's health behaviours in relation to GP service use.

Finally, South Asian women and access to cervical cytology is a good example of a service through which to examine both 'race' and gender dimensions of access. The gender dimensions of access are immediately relevant. Cervical cytology is a preventative service which recognises the unique health needs of women (McKie, 1995). It has been prioritised as a key women's health issue and has attracted mainstream support, policy responses and resources. Cervical cancer is a growing problem for all women. The literature shows that screening has a possible preventative effect and is helpful in tackling some aspects of the problem. Questions of access to screening are therefore important. The importance of such questions is reinforced by some tentative evidence which shows that rates of cervical cancer among South Asian women may be different or higher than those of the majority ethnic population (Matheson *et al.*, 1985; Donaldson and Clayton, 1984).

This healthcare arena also adds to debates about access. The use of cervical cytology services challenges conventional patterns of service use in two ways. Firstly, the use of this service modifies the learned patterns of service use. Health services are conventionally used when someone is ill. Cervical cytology urges women to use health services when healthy. It is considered to be good health behaviour to attend for cervical cytology every 3 years (in Lothian) for most of a woman's adult life. Secondly, cervical cytology is a preventative service marking a shift in the nature of health interventions in primary care from cure to prevention. It encourages women to take responsibility for the management of their health and to maintain health through the use of health services. It therefore blurs the boundary between healthcare outside and inside health services.

For South Asian women the 'race' dimensions of access are also apparent. The issue of cervical cytology and South Asian women demonstrates the persistence of the role of cultural factors, and the influence of assumed and problematic South Asian cultures, in explanations of access to the service. It is a good example through which to challenge approaches which presume access difficulties result from what is constructed as 'South Asian culture'. South Asian women's patterns of service use have been pathologised and been subject to culturally racist explanations. In contrast to the assumption that South Asians overuse the GP service, it is widely assumed that South Asian women use cervical

cytology services less than other women, on account of their culture. It is assumed that they have little understanding of cervical cytology and are constrained in their use of the service. This has meant that explanations of poor uptake rates have centred on the assumptions that South Asian women do not comply with, or are not motivated to use, cervical cytology services.

The assumption that South Asian women do not attend for cervical cytology services due to cultural constraints has a number of wider implications. Firstly, it is inferred that South Asian women are irresponsible, or are 'bad' patients who are a danger to their own health. In effect, the cause of access difficulties becomes located within the minority ethnic communities themselves. Secondly, this type of explanation implies that women would attend if they are educated out of their beliefs and anxieties. Thirdly, it also implies that women need to adapt to health services, not that health services might need to adapt to the users of services themselves. Like access to the GP service, the pathologisation of South Asian women's health behaviours and beliefs has affected conventional understandings of access to this service. This overshadows women's experiences and perspectives as well as the shared gender and the 'race' dimensions of access to the service.

All healthcare arenas contribute to debates on access to healthcare and to debates on women's health and the health of minority ethnic groups. Having outlined my research frame I will now turn to the presentation of the data and the terminology used.

1.7.2 Note on the presentation of the analysis of ideas about 'race' and gender difference and access to healthcare

I have argued above that studies must be designed to examine the cultural, 'race' and gender dimensions of access to healthcare for South Asian women. My study design as well as the presentation of results was designed with this in mind. The challenge was to comment on the material in the most useful way in the light of the debates outlined above.

One of the main difficulties in exploring minority ethnic women's experiences and perspectives of health and healthcare is to find ways of expressing the interrelationships of 'race' and gender difference (Douglas, 1992) as external constraining influences on access to healthcare. For analytical purposes the findings on the collective dimensions of access are presented in two main sections: the effects of ideas about 'race' difference on access, and the effects of ideas about gender difference on access to healthcare. Each empirical

chapter considers which factors affecting access can be attributed to 'race' and to gender difference and examines how perceptions and experiences of gender and 'race' difference operate for the South Asian women interviewed. The aim is not to separate out or to isolate the operation of each dimension but to allow the reader to appreciate both 'race' and gender dimensions of access to healthcare for South Asian women.

1.7.3 Note on terminology

The use of terminology denoting minorities is problematic. I accept that choices in terminology are difficult to make and that all terms have strengths and weaknesses. However, for pragmatic purposes research is forced by the history of studies on 'race' difference to use particular terminology it might otherwise move to challenge. I have chosen to use the term 'minority ethnic groups' because it refers to sections of the population and their experiences in relation to the 'majority ethnic' population and to those that may experience discrimination and inequality on account of skin colour, heritage, way of life, language or religion. My use of the term also signifies that ethnicity is possessed by everyone not just those readily identifiable as belonging to some distinctive sub-population. However, when making reference to studies that have used other terms, for example 'black' in its political sense to refer to non-white populations and to the common experience of racism, these terms will be used.

The use of terminology referring to particular minority ethnic groups is also problematic. Studies have challenged the uncritical and inconsistent use of the term Asian in health research (Johnson, 1993b; Ahmad and Sheldon, 1992; Bhopal, 1992; Bhopal, Phillimore and Kohli, 1991). The term Asian has informed explanations of patterns of health and access to healthcare and social policy. It may have become a barrier to recognising the needs of South Asian groups (Travis, 1994). The term Asian does little to show the heterogeneity that exists among this group in terms of region, for example. Other studies have criticised use of the term 'black'. Modood (1994, 1988) suggests that this term minimises the differences between black groups but also promotes the interests of some groups over others. After a consideration of these arguments, I have chosen to use the term South Asian to refer to those from or who are descended from those who were born in the Indian subcontinent (i.e. India, Pakistan or Bangladesh). My study includes the views and experiences of women whose heritage represents the four main South Asian ethnic categories present in Edinburgh (see section 2.3). Throughout the chapters I aim to illustrate the range of responses gained.

Where relevant I shall demonstrate differences in experiences and views among the four South Asian ethnic categories included, but use the term South Asian where women's experiences are similar, noting that other work (e.g. Brah, 1992) suggests that the processes of racialisation are similar for South Asian women as a category. The term white is used somewhat interchangeably with 'majority ethnic population'. I recognise that the former scarcely represent a unitary ethnic identity, however, I follow the terminology used in the studies cited throughout the thesis.

Finally, I use the term 'race' in inverted commas, to acknowledge that the notion of 'race' difference is a social construction and that 'races' are not real. The aim is to remind the reader that I am contesting the notion of 'race' as an explanatory variable and to remind him/her of the long history of the use of the word 'race' as if 'races' were real. Several geographers (Smith, 1989) and other social scientists (Smaje, 1995; Ahmad, 1993a; Bowes and Domokos, 1993; Lawrence, 1982) adopt this approach for similar reasons.

1.8 Conclusion

This chapter has outlined the background to my study and has set the scene for the original empirical work described next. It has presented a critical review of the existing literature, in the light of which it has outlined my own research which focuses on access to healthcare in three different healthcare arenas: healthcare outside services, the GP service and cervical cytology services.

Two main conclusions can be drawn from this chapter. Firstly, there is a need for a broader understanding of the theme of access to healthcare for South Asian women. Secondly, minority ethnic women's healthcare experiences and perspectives are invisible in a number of areas of relevant literature.

On the need for a broader understanding of access to healthcare, I have argued that 'access' and healthcare are in fact much broader concepts than much of the literature implies. Studies which conceptualise access to healthcare as the uptake of services and physical distance to caring services allow only a partial understanding of access to healthcare among South Asian women. Further, healthcare is more than the use of health services. In order to understand these broader notions of 'access' and healthcare we require better information about people's own perspectives on, and experiences of, healthcare. The latter point is the central argument of my study. Minority ethnic groups' own perspectives and experiences of

healthcare will help to challenge conceptualisations of 'access' that underplay differences and inequalities in patterns of healthcare between social groups. They will also challenge understandings of 'access' that contribute to the general invisibility of minority ethnic groups' experiences and perspectives in healthcare provision.

The need for a broader conceptualisation of access to healthcare which is sensitive to the perspectives and experiences of South Asian women is highlighted in four areas of literature which reveal the invisibility of minority ethnic women's healthcare experiences and perspectives in debates on health and health service inequalities.

Firstly, the literature on women's health is generally 'race' blind. It has not understood or challenged the position of minority ethnic women and issues of access to healthcare. Secondly, the literature on minority ethnic groups and health is generally gender blind. Studies on minority ethnic groups have tended to emphasise culture or to a lesser extent ideas about 'race' difference or to an even lesser extent ideas about gender difference as factors affecting minority ethnic groups' health, healthcare, lifestyles or lifechances. The result has been that an emphasis on one factor at the expense of others obscures an understanding of minority ethnic women's own situations, experiences and perspectives. In particular, analysts have been preoccupied with cultural explanations for minority ethnic groups' health experiences which draw on constructions of minority ethnic culture. Less is written about minority ethnic groups which uses a conceptualisation of culture as people's world views which draw on a shared fund of ideas and individual lived experiences (Bowes, Dar and Sim, 1995). This has added to the invisibility of minority ethnic women's experiences and perspectives by smokescreening an examination of the effects of structural factors on minority ethnic groups' access to healthcare and by focusing on the attributes of minority ethnic groups rather than on the attributes of services or on minority ethnic groups' ideas about, and experiences of, services. Explanations for minority ethnic groups' health experiences which use constructions of culture have contributed to the construction of minority ethnic groups' health problems, affected responses to inequalities in access, affected understandings of health and healthcare needs and the identification of research issues. Another lesser focus of interest has centred on ideas about 'race difference and health. However, it too has contributed to the invisibility of minority ethnic groups' healthcare experiences and perspectives. This research has tended to use 'race' as an explanatory variable rather than as a marker of differences that require explanation.

In the light of such literature, studies need to consider women's world views and the 'race' and gender dimensions of access if progress is to be made in understanding South Asian women's access to healthcare.

The invisibility of minority ethnic women's healthcare experiences and perspectives has also been highlighted in a third area, in my review of the small but growing number of studies on minority ethnic groups in Scotland. More work, therefore, needs to focus on the Scottish experience. Finally, this invisibility has been shown in my discussion of health policy targeted at three levels - at women, at minority ethnic women and at minority ethnic groups. The strongest criticisms have been that policy responses targeted at minority ethnic groups and minority ethnic women have focused on internally generated practices. They have not adequately considered the attributes of health services. Further, policy has been insensitive to structural issues in service delivery and in the healthcare experiences of minority ethnic groups that may affect access to healthcare and thereby legitimate these as areas for concern.

In the light of these debates about access to healthcare, the invisibility of minority ethnic women's healthcare experiences and perspectives, and in setting my research frame this thesis focuses on access to three different healthcare arenas - healthcare outside services, the GP service and cervical cytology. Each arena contributes to a bigger picture of South Asian women's access to healthcare. They challenge the invisibility of minority ethnic women described above, signify a move away from disease centred research in the literature on minority ethnic groups and health and from understandings of access to healthcare that conceptualise access as the uptake of, and physical distance to, services, toward a focus on South Asian women's healthcare experiences and perspectives.

Having set the research frame and outlined a range of relevant debates the next step is to examine how research is done and how it can best illuminate understandings of access to healthcare for South Asian women. The next chapter focuses on this problem in detail.

Methodological Approaches

2.1 Introduction

It is the aim of this chapter to present a theoretical and empirical account of methodological issues arising during the course of my study. Having set the research problem, which is the point of departure of the study, and outlined theoretical debates and background in chapter 1, I aim now to give an account of the evolution and implementation of my study. As well as laying out my key methodological concerns this is in line with a need for self-consciousness in the presentation of results (Dobash and Dobash, 1992) and a need to describe the process of doing research (Mooney, 1994; Oakley, 1988).

I consider issues of research design and sampling and describe the circumstances under which the accounts of the women interviewed were gathered. I also outline issues arising during the process of carrying out the research, the research instruments used, and the process of analysis and writing up. Throughout I reflect on the strengths and limitations of the approaches taken and evaluate alternatives. This allows the reader to judge the claims made in the text and gives pointers for further work. Further, I consider current methodological debates in research on women and minority ethnic groups that focus on the interviewing process, the issue of who conducts research and the negotiation of power in the interview situation. The chapter ends with an assessment of the interview process itself and the nature of the interaction between me as the researcher and the women interviewed.

As highlighted in chapter 1, my study aims to start with women's own healthcare perspectives and experiences to inform understandings of access to healthcare and is critical of approaches and research questions that have predefined, rather than reflected on, the concerns and experiences of South Asian women themselves. This chapter supports other work which emphasises that the health attitudes and actions of racialised groups must be uncovered, examined and analysed in appropriate and sensitive ways that aim to encourage advocacy in healthcare (Bowes and Domokos, 1996). My premiss is that women need to be encouraged to represent their own views and that researchers need to respond accordingly.

2.2 A Qualitative Approach

Qualitative approaches to research comprise a diversity of methods and techniques. They cannot be reduced to a set of stages or tools (Bryman and Burgess, 1994). In this section, some fundamental features of qualitative work are selected and their potential for my study is discussed. The research problem set out in chapter 1 guided the research design, methodological detail and the presentation of results. My methodology had to be capable of eliciting information on access to healthcare in its broadest sense, and this required sensitivity to women's views and experiences of healthcare. It also had to elicit understandings and experiences from three different healthcare arenas. Given the aims of my study I was drawn to the increasing amount of work in the field of minority ethnic groups and healthcare which has used qualitative methods (Bowes and Domokos, 1995b, 1995c, 1993; Donaghy, 1995; Anionwu, 1993; Bowler 1993a, 1993b; Fenton and Sadiq, 1993; Leeds FHSA, 1992; Curren, 1991, 1986; Thorogood, 1988; Donovan, 1986; Homans, 1980). All these studies aimed to make sense of minority ethnic groups' views and experiences of healthcare.

Table 2.1 summarises the continuum of properties of qualitative and quantitative methods. I shall now elaborate on some of the points in the table and assess their strengths and weaknesses in terms of my study.

	QUALITATIVE	QUANTITATIVE
SAMPLE	Theoretic sample	More likely to be random sample
EMPHASIS ON	Intensive coverage and depth of understanding	Extensive coverage and breadth of understanding
SCALE	Resources used to glean maximum detail from minimum number of cases	Resources used to secure 'minimum' detail from a maximum number of cases
AIM	To understand processes	To describe patterns and trends
E.G. IN HEALTH RESEARCH	Complex behaviours, health actions, perceptions, experiences, pathways into healthcare	Rates of service use, test effects of a health intervention
DATA COLLECTION EMPHASISES	Open-ended questions. Can be responsive to subjects' agenda	Can be closed-ended questions. Oriented to researchers' agenda
TYPES OF RESEARCH TOOLS	In-depth interviews, semi-structured interviews, unstructured interviews, focus groups, observation, case study	Structured interviews, survey, postal questionnaire
FORMAT DATA IS RECORDED AND ANALYSED	Unstructured data	Structured data
ANALYSIS	Preserves interviewees' concepts and dialogue	Reduces raw data to a minimum number of standardised categories

	QUALITATIVE	QUANTITATIVE
OUTPUT	Theoretical generalisations about the meaning of relationships and events. Non-statistical representation of phenomena	Statistical generalisations about the wider characteristics of a population based on inferences from the sample

Table 2.1 Qualitative and Quantitative Research Techniques with reference to health research

Chapter 1 argued that explanations of South Asian women’s access to healthcare need to be grounded in the perspectives and experiences of South Asian women themselves. Without understanding the factors that affect this group’s access to healthcare I could not measure the effects of predefined factors on access. The challenge was to shed light on the problem of access and to explore factors enabling and constraining access to healthcare. Comparing different approaches qualitative research techniques would allow me to gain a detailed understanding of, and to explore issues affecting, access to healthcare for this group.

Qualitative research techniques also allowed me to adopt a user-orientated approach and to be responsive to the interviewees’ perspectives. Such techniques were chosen because I judged that they would give sufficient descriptive and interpretative material to provide an understanding of the meanings and motives behind health behaviours that quantitative techniques can only describe. Therefore, I judged that such techniques would allow me to move beyond the idea of access to healthcare as the uptake of services and help me to build a detailed picture of women’s pathways into healthcare as well as their perspectives on, and experiences of, healthcare in the three chosen healthcare arenas.

This type of approach allowed me to employ open-ended questions and to move away from standardised or closed questions employed in quantitative studies. Qualitative research techniques involve the acquisition of data that cannot be accommodated within predefined categories and imply that single or unified explanations of behaviours, views and experiences are problematic (Opie, 1992). Such techniques would avoid forcing women into opinions they did not really hold. Given the stereotyped research questions and the construction of minority ethnic groups’ health problems criticised in chapter 1, I judged that qualitative research techniques might allow me to gain material to challenge stereotypical assumptions about South Asian women's health experiences and behaviours.

In addition, qualitative research techniques emphasise the depth and detail of understanding rather than the breadth of understanding. In terms of this study, potentially they would

allow me to move away from deterministic explanations of minority ethnic group's access to healthcare that stress either 'race' gender or culture. Such techniques would help me to reveal the richness and variety of subjects' responses (New and Senior, 1991), and to give weight to a range of positions, perceptions and experiences affecting South Asian women's access to healthcare.

Finally, qualitative research techniques would help me to consider points of difference between competing accounts and to examine minority views alongside majority views. Similarly, this would help me to understand the differences and commonalties in access to healthcare between South Asian women and other categories of women documented in the literature.

Having outlined the strengths of qualitative research techniques and related some of them to my study, I will now examine issues of sampling and gaining access to the women interviewed.

2.3 The Research Sample

Below I trace the process of sampling and justify the approaches used. I consider practical, theoretical and political factors and show that my sampling strategy was linked both to the development of theory and to the demands of the research setting (Hammersley and Atkinson, 1983).

Table 2.1 shows that qualitative approaches tend to use non-probability methods of sampling or theoretic sampling where interviewees are determined by theoretical development. The logic of sampling in qualitative approaches differs from that employed in quantitative research. It emphasises the quality of information that people can offer, rather than the number, representativeness or typicality of those included (McCracken, 1988). Theoretic methods are purposive and are commonly used where the chance of selection for each element in the population is unknown or zero (Arber, 1993). To examine South Asian women's access to healthcare in a number of healthcare arenas, I decided that it was more important to work out the best sampling strategy to gain an information rich sample than to guarantee the representativeness of the data. My need to gain a detailed understanding of access to healthcare that is sensitive to the concerns of South Asian women meant that it was more important to emphasise the depth rather than breadth of understanding.



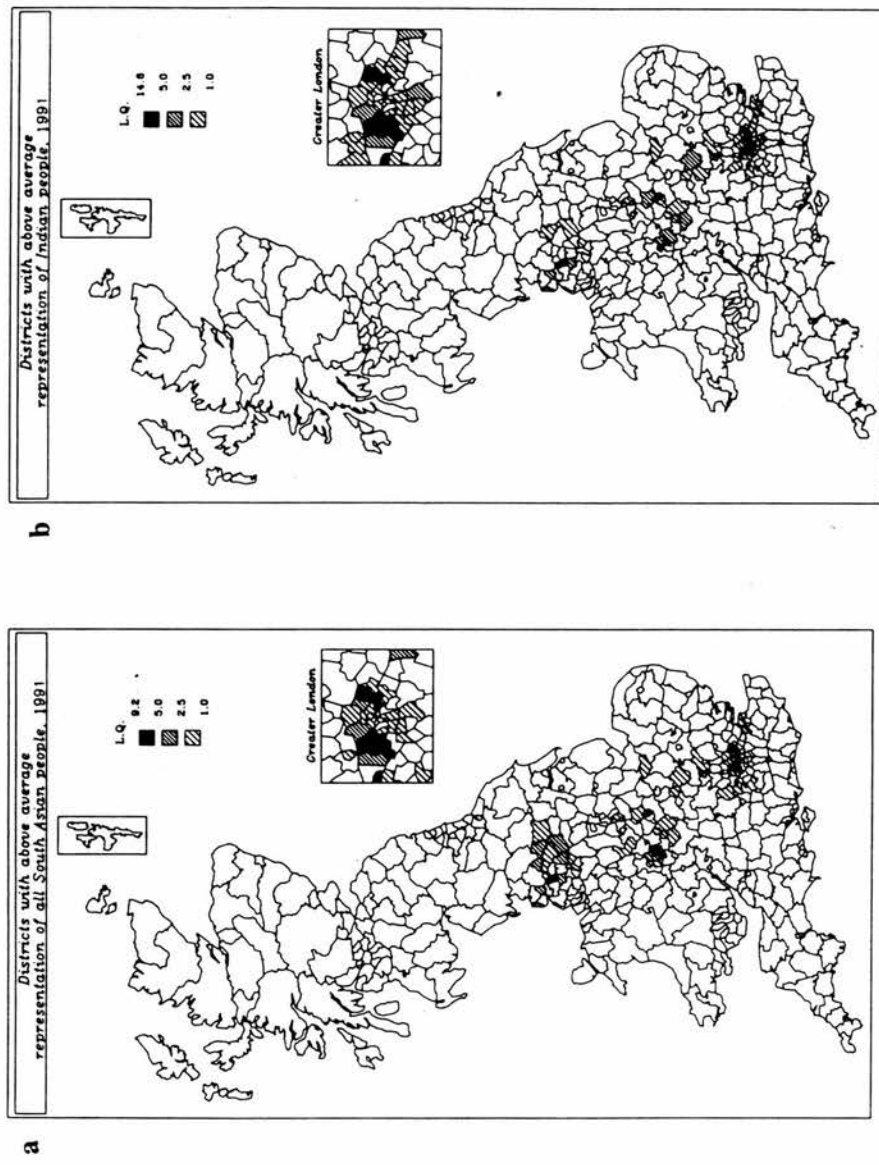


Figure 2.1 The distribution of South Asian groups in the UK (from Owen, 1991)

a. The distribution of all South Asian population in the UK. b. The distribution of the Indian population in the UK

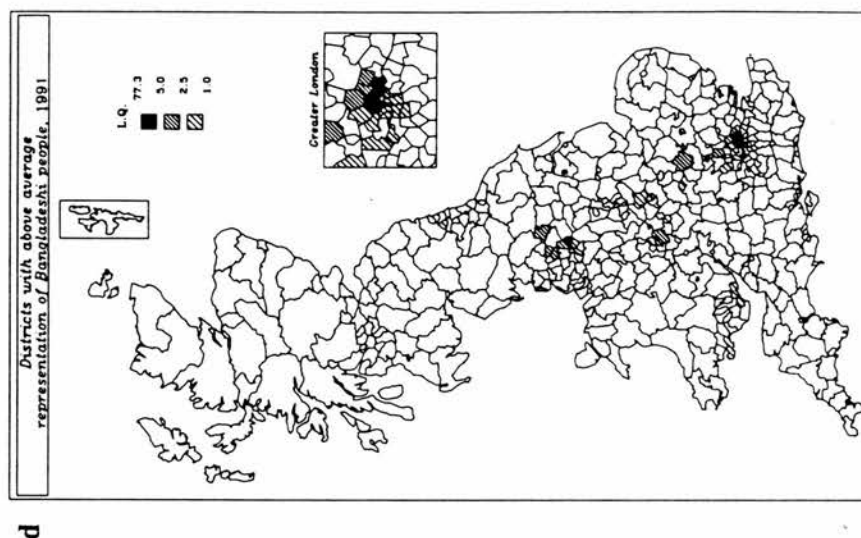
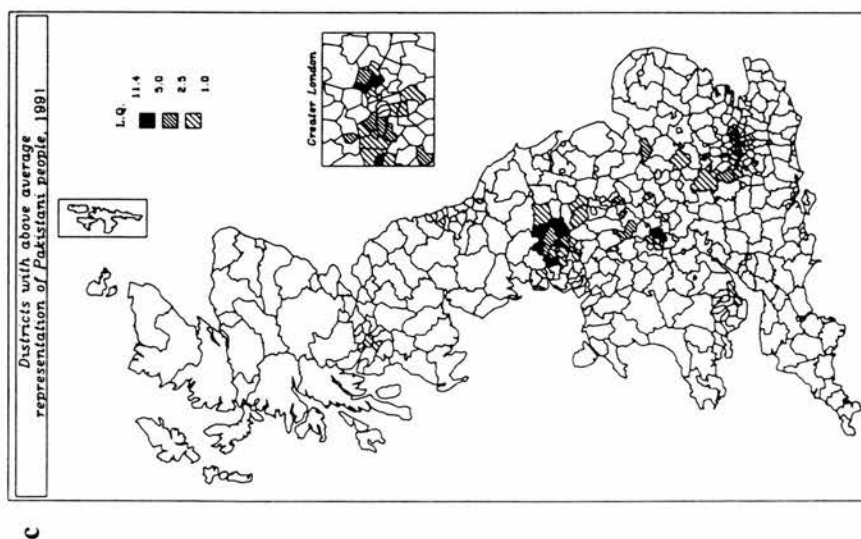


Figure 2.1 (continued) c. The distribution of the Pakistani population in the UK d. The distribution of the Bangladeshi population in the UK

My decision to focus on South Asian women's access to healthcare was influenced by a number of theoretical, practical and personal factors. Minority ethnic groups of South Asian heritage make up a large proportion of the minority ethnic population in the UK and an even larger proportion of that in Scotland (Table 2.2). South Asians in the UK comprise over half the non-white population (Smith, 1989). Indians are by far the largest group, followed by Pakistanis and then Bangladeshis (Owen, 1994). The composition of Indian, Pakistani and Bangladeshi populations varies according to generation. Bangladeshis exhibit a greater proportion of first generation men and women than the Indian population for example. The 1991 Census shows that 42.3% of Indian men and 41.6% of Indian women were born in the UK, compared to 50% of Pakistani men and 51% of Pakistani women, and 35.5% of Bangladeshi men and 37.9% of Bangladeshi women. Figure 2.1 depicts the distribution of South Asian groups in the UK, Scottish figures, which are not included on the maps, are discussed below. It shows that there are wide variations in the ethnic composition of the British population and that South Asian populations have different spatial distributions. Smith (1989) describes the polarisation of South Asians at a variety of spatial scales. Owen (1994) shows that Pakistanis have a greater orientation to Northern England and the Midlands than the South East. Populations are greatest in West Yorkshire and the Midlands. Bangladeshis have a more concentrated distribution and are mainly located in Greater London, which contains over half the total Bangladeshi population, Greater Manchester and West Midlands Metropolitan County. In contrast, the majority of Indians live in the South East and West Midlands, with a substantial number in the East Midlands and the North West of England.

In Scotland according the 1991 Census, minority ethnic groups are concentrated in the four cities of Edinburgh (with 16% of Scotland's total minority ethnic population), Glasgow (34%), Dundee (5%) and Aberdeen (5%). Minority ethnic groups make up 1.3% of Scotland's population (total, 63,957) and 1.7% of the population of Lothian (total 12,342) (see Table 2.2)

Ethnic category	% of total pop. in Lothian Region	Total number in Lothian	% of minority ethnic pop. in Scotland	Total number in Scotland (% of total pop.)
Indian	0.2	1370	16.05	10050 (0.20)
Pakistani	0.5	3270	33.83	21192 (0.40)
B/deshi	< 0.05% of pop.	331	1.81	1134 (0.00)
Chinese	0.3	2231	16.73	10476 (0.21)
Other Asian	0.3	1161	7.34	4604 (0.09)
Black African	0.1	710	4.43	2773 (0.06)
Black Caribbean	< 0.05%	228	1.49	934 (0.02)
Black Other	0.1	531	4.22	2646 (0.05)
Other	0.3	2158	14.09	8825 (0.18)

Source: 1991 Census, Crown Copyright

Table 2.2 The minority Ethnic population in Lothian and Scotland

Given that South Asian women make up a large proportion of the minority ethnic population in Scotland, the heterogeneity of the South Asian population and my own partly South Asian heritage I decided to focus on South Asian women. This was fuelled by my own experience and the need to know about South Asian women in the UK.

The interviews were all conducted in Lothian, mainly in Edinburgh. Edinburgh was chosen for a range of reasons. Chapter 1 pointed to the invisibility of minority ethnic groups' experiences and perceptions in research into health and healthcare in Scotland. Most related research has taken place in Glasgow where the South Asian population is significantly larger than in Edinburgh. Table 2.2 shows that a significant South Asian community exists in Lothian and my study casts some light on South Asian women's healthcare experience. My decision to carry out the study in Edinburgh was influenced to a certain degree by background knowledge about South Asian groups in Lothian gained from voluntary and crèche work at a number of voluntary groups which have South Asian women among their clients. It was also influenced by more general knowledge gained through living in Edinburgh during the course of the study. This knowledge gave me insight into a number of access issues, the women's voluntary sector and also allowed me to identify areas where I might gain access to potential interviewees.

The issue of a comparative study

When planning the study I considered the possibility of using a comparative study design to examine the issue of South Asian women's access to healthcare. According to Stanfield

(1993) it is commonly regarded as imperative for studies on minority ethnic groups to be conducted using a majority ethnic/white comparison. Such an approach is deeply rooted in the epidemiological literature. For example, Bhopal and Rankin (1996) argue that in the study of cancer, priorities for minority ethnic groups have been set on the basis of comparisons with the majority ethnic population rather than on the basis of actual number of deaths from cancer within minority ethnic groups and this has led to a focus on cancers that are more common among minority ethnic groups. My decision not to undertake a comparative design was taken after an assessment of the advantages and disadvantages of such an approach and was informed by my critical review of the literature presented in chapter 1; the practicalities of conducting the study; and by the limited amount of work focusing on issues of 'race' and ethnicity and research methods, in particular, by work that has called for an examination of what is taken for granted in methodologies in studies focusing on minority ethnic groups and health (Bhopal and Rankin, 1996; Stanfield, 1993).

Firstly, it was felt that a comparative study design was not appropriate to the research problem as it would have shifted the focus of the research toward a different set of research questions. My study aimed to examine the issue of South Asian women's access to healthcare by incorporating South Asian women's experiences and perspectives and to give South Asian women a voice which so much research denies. My study did not aim to compare the healthcare experiences and perspectives of South Asian and majority ethnic women or to demonstrate differences in access between the two groups of women (as other studies in the field have done e.g. Williams *et al.*, 1993; Howlett *et al.*, 1992). A study comparing the experiences of South Asian and majority ethnic women was seen to have been of greater value if my study had aimed to add to the evidence that South Asian women may be disadvantaged in terms of access to healthcare. However, my aim was not to describe or measure inequalities in access but to use this as the starting point of my study and to move on to understand the factors and processes that affect South Asian women's access to healthcare. This was judged to be important because, as noted in chapter 1, minority ethnic group's health experiences have not been adequately described, let alone explained (Smaje, 1995), and minority ethnic women's experience of access to healthcare has been neglected in the literature on minority ethnic groups and health and on women's health.

A comparative study might have been advantageous had I aimed to identify the range of factors that affect women's access to healthcare and then to ascertain how far the factors

were distinctive for South Asian women. In this respect, a comparator group might have helped me to gain a more precise understanding of where particular factors come into play or appear stronger in the experience of South Asian women (Bowes, personal communication and work in progress, Stirling University). A comparator group might also have helped me to elaborate on themes (Ragin and Hein, 1993) and to gain a more comprehensive picture of the issues arising in the interviews and, therefore, it might have helped me to increase an understanding of the factors affecting South Asian women's access to healthcare.

However, my study aimed to gain an understanding of access to healthcare that was sensitive to the perspectives and experiences of South Asian women and to see South Asian women's perspectives and experiences as valuable in their own right as called for in the literature on minority ethnic groups and health (Ahmad, 1993a; Bhopal 1992). Overall, I judged that a focus on a comparator group as well as South Asian women would have urged me to attach more importance to the comparison of experiences and perspectives, than to South Asian women's own experiences and perspectives. Therefore, it would have decreased the sensitivity of the research to South Asian women's healthcare experiences and perspectives. It might also have constrained my ability to highlight the range of experiences and perspectives among the South Asian women interviewed and, therefore, it might have compromised the depth of understanding gained.

Secondly, a comparative study was judged to present a number of disadvantages in the light of the wider literature discussed in chapter 1. A comparative study would have involved matching South Asian women with majority ethnic women in similar circumstances and with the same relevant characteristics (Miles and Huberman, 1984). However, the use of a majority ethnic comparator group implies that one needs to control for ethnic group. Following my review of the wider literature in chapter 1, I judged that ethnic group was not the only factor affecting South Asian women's access to healthcare. A non-comparative study design then aimed to move away from approaches which have given ethnicity overarching importance in studies on minority ethnic groups and health as shown in chapter 1. Further, a comparative study design was complicated by the fact that we do not know the factors that affect South Asian women's access to healthcare. In terms of the methodological approach taken then, it was not clear which characteristics needed to be matched in a study focusing on South Asian women's access to healthcare. It was, therefore, not possible to control for the experiences of the South Asian women in the study.

This is reinforced by the data gained which shows uneven numbers and types of experiences among the South Asian women interviewed as well as complex sets of experiences which are not 'encapsulated in the idea of a 'characteristic' of a person' which can be used to classify women for the purposes of comparison (Mason, 1996: 96). The interview data also show that the experience of the women interviewed is too diverse to be able to match women or to draw a meaningful comparative group.

The decision not to undertake a comparative study was also backed up by a range of theoretical debates and criticism of the need for comparative studies in the small amount of literature on 'race' and ethnicity and research methods (Douglas, 1996b; Stanfield, 1994, 1993). Underlying the need for comparative studies in work on minority ethnic groups are a number of assumptions which have shaped research approaches in studies focusing on minority ethnic groups. These have wider implications for research in the field.

Firstly, it is assumed that minority ethnic groups and their experiences and perspectives are 'not relevant enough to stand on their own two feet in analysis' (Stanfield, 1993: 27) unless seen against a comparative group. Secondly, the use of, in this case, majority ethnic women's experiences and perspectives in interpreting the data implies that the experiences and perspectives of South Asian women need to be validated against the experiences of majority ethnic women (Douglas, 1996b). Thirdly, such a research approach assumes that arguments presented in research on minority ethnic women are strongest when evidence is drawn from more than one category of women (Stanfield, 1993). Fourthly, the emphasis on a comparative approach reflects the idea that majority ethnic group's realities can be generalised to explain the realities of minority ethnic groups' lives (Stanfield, 1993). The uncritical application of majority ethnic group's experiences and perspectives to those of minority ethnic groups has been highlighted as an issue of concern in future research focusing on minority ethnic groups (Wrench and Reid, 1990). In the current study, it was felt that such a practice would have privileged majority ethnic women's experience as the 'norm' and that this would have influenced theoretical development and data interpretation. This ethnocentric tradition in social research is long-standing and it reflects the tendency not to develop methodologies which are grounded in the indigenous experiences of minority ethnic groups (Stanfield, 1994).

Further criticism of the assumptions behind the need for comparative studies in research on minority ethnic groups is all the more telling when we consider the wider literature on

women's health and health more generally. In contrast to studies focusing on minority ethnic women, in studies focusing on majority ethnic women it is not viewed as legitimate to validate the experiences of majority ethnic women against those of minority ethnic women. Indeed the issue of minority ethnic group comparisons in studies focusing on majority ethnic women's health is a non-issue in debates about methodology. In addition, it is not viewed as legitimate to use the realities of minority ethnic women's lives to explain the realities of majority ethnic women's lives.

More often than not it is envisaged that the presence of minority ethnic groups in studies would complicate the analysis (Stanfield, 1993). In empirical studies on health for example, it is common to select samples without including minority ethnic groups (Craig and Rai, 1996; Thompson, Douglas and McKee, 1994). Often the omission of minority ethnic groups is not acknowledged. On the off-chance, research may include notes explaining why minority ethnic groups have been excluded. For example, Foster's (1995) recent book 'Women and the Healthcare Industry' does not include an analysis of the position of minority ethnic women because of the lack of empirical evidence about how the factors/issues she discusses affect minority ethnic groups and about whether such groups are affected differently from majority ethnic women.

These themes in the wider literature on women's health and the assumptions underlying the emphasis on comparative studies in research on minority ethnic groups have a number of wider implications. Firstly, the emphasis on comparative studies reinforces the marginalisation of minority ethnic groups in health research and the marginalisation of their own experiences and perspectives in research and research design. Secondly, this emphasis perpetuates the view that minority ethnic groups are 'hard to reach and hard to research' (Douglas, 1996b). Finally, it reinforces a situation where according to Rai (1995) the most common methodological approach for addressing Asian communities in social research is the partially visible approach, where little attention is paid to conceptualising the research problem within the context of the minority ethnic group's experiences and where analysis is carried out with reference to the experience of white communities.

My focus on South Asian women alone goes some way toward challenging tokenistic acknowledgement of minority ethnic groups in research, a situation where such groups' experiences are undervalued in research and an emphasis on methodological approaches which do not support minority ethnic group's views and experiences as valid in their own

right. It also moves to challenge the prioritisation of majority ethnic women's experiences at the expense of sensitive research approaches which aim to understand South Asian women's experiences and perspectives.

The advantages and disadvantages of a comparative study were also examined in the light of the practicalities of conducting such a study. The practical constraints on the project and the time and resources available to it also meant that conducting a majority ethnic comparison was not a realistic option.

A comparative study would have meant conducting double the number of in-depth interviews (in this case 72 interviews) and this, given the limits on the resources (e.g. to fund travel and equipment) and time available (e.g. for interviews, transcription, second interviews and for data analysis) meant that it was not a practical option and might have even compromised the timely completion of the project. In addition, I judged that conducting double the number of interviews might have compromised the sensitivity of the study to South Asian women's healthcare experiences and perspectives. It was envisaged that the time taken to conduct interviews with a comparator group as well as the sheer bulk of the data gained might have compromised my ability to gain detailed knowledge of each case.

Following on, as noted above, a comparative study would have entailed matching the South Asian women interviewed with a sample of majority ethnic women. Whilst this was not considered to be the best way forward on theoretical terms because the criteria for the selection of a comparative group were not clear, the practicalities of the research situation reinforced my decision not to undertake a comparative study. In terms of the time taken to gain access to the comparative sample, my experience as the sole researcher on the project showed that it took the best part of year to set up contacts with the voluntary sector, find interpreters and contact and negotiate with potential key informants and potential interviewees. This was in addition to the time taken to set up interviews and for travel (see section 2.4). A comparative study would have meant that this process would have had to have been repeated for majority ethnic women and, in the light of my theoretical criticism above, it would have taken up a disproportionate amount of time.

An alternative strategy to gain access to potential interviewees might have allowed some form of a comparative group to have been drawn at the same time as the South Asian women. For example, a study by Morgan (1996) on hypertensive patients drew both an

Afro-Caribbean sample and a white comparative sample from a number of GP patient lists. This approach was thought not to be a practical option given the research situation, in particular the small South Asian community in Edinburgh, given the range of difficulties in contacting certain groups e.g. Bangladeshi women and given my aim not to contact women through services (see section 2.4). It might have also compromised the timely completion of the project.

In the light of the small amount of work in the field of minority ethnic groups and health that has been supported by empirical evidence, practical arguments and my theoretical criticism of the need for comparative studies, the lack of a comparator group should not be seen as something to minimise the importance of my findings. Other useful studies have focused solely on minority ethnic groups (e.g. Bowes and Domokos, 1995b, 1995c; Williams R., 1993; Donovan, 1986) and have developed successful methods to do so. In the end, the use of the wider literature on women's healthcare was considered to be more important than conducting a comparative study. In the face of limited time and resources, I considered that it was more important to draw connections between my own findings and other related research and therefore to use the literature on majority ethnic women's healthcare alongside the literature on minority ethnic groups and health to analyse the empirical data. The literature on women's healthcare was used to form questions and to inform findings. In the same way, minority ethnic women's experiences and perspectives need to inform work on women's health more generally. As noted in chapter 1, it was envisaged that work on minority ethnic women's access to healthcare might generate recommendations that might also lead to improvements in access to healthcare for majority ethnic women.

The selection of cases

The selection of cases in the theoretic sample was informed by the increasing recognition of the heterogeneity of minority ethnic groups in the UK (Travis, 1994; Jones, 1993; Barker, 1993; Brah, 1993, 1992; Bhachu, 1985). A central criticism of past work on South Asian groups and health has been that the South Asian ethnic category obscures an understanding of the heterogeneity that exists in these communities in the UK. This is in some ways symptomatic of the dearth of studies on South Asian groups' perspectives on, and experiences of, healthcare. If user views are to inform understandings of access to healthcare, studies need to challenge stereotypical notions of South Asian ethnic categories

(Brah, 1993; Bowler, 1993a). One way to do this is to include the heterogeneity that exists among South Asian ethnic categories in the study area.

A number of studies on South Asian women's health have concentrated on Pakistani Muslim populations (e.g. Bowes and Domokos, 1995c, 1993; Brah, 1993; Fenton and Poonia, 1988). Some have tried to take into account the heterogeneity that exists by arguing that their study populations are roughly representative of South Asian groups in their study area. Fenton and Poonia (1988) and Homans (1980) for example, include small numbers of Indian women in proportion with the Indian population in their study areas. In Edinburgh, such an approach would have meant a sample of 23 Pakistani women, three Bangladeshi women and 10 Indian women (both Sikhs and Hindus) based on CRE estimations (CRE, 1991). I decided against this sampling strategy because I wanted to include views from all parts of the South Asian community without privileging some simply because of numerical dominance. I therefore decided to include the four main South Asian ethnic categories present in Edinburgh in equal numbers: Pakistani, Bangladeshi, Sikh and Indian (of Hindu heritage). This enabled me to acknowledge the heterogeneity that exists, to give each ethnic category equal weighting and to contribute to theory development.

The next step was to determine which people to approach within the defined population. One sampling strategy was to sample in different age groups. I thought that this would add to an understanding of access to healthcare for South Asian women and the breadth of information gained. The sample includes women from four South Asian ethnic categories across the age range. The youngest interviewee was 23 and the eldest 67 (see section 2.5 for summary). The healthcare arenas I had chosen revealed no obvious limitations in terms of the age range within which to target potential interviewees. The GP is a mainstream service that is generally available to all and cervical cytology is available in Lothian between the ages of 20-60 and to women over 60 on request.

The next sampling strategy was to explore a range of healthcare experiences. This meant that I needed to include women who used a range of different health services. In addition, I decided to include women who had a good command of English and women who spoke little or no English. In common with other studies (Bowler, 1993a, 1993b), I thought that the latter group might have the least favourable experience of healthcare. However, in chapter 1 I criticised explanations of access to healthcare which have reduced all constraints on access

to language problems. It was, therefore, important to include women who could speak English alongside those who could not.

Sample size

A total of 36 women, nine women in each South Asian ethnic category, were interviewed. The number of cases included in the current study was determined by expediency. Indeed, the literature on sampling shows that the determination of sample size in qualitative research is not a straightforward process and is complicated by the fact that conventions for sampling are less well documented in qualitative as compared to quantitative research (Mason, 1996). The process of determining the final number of cases was informed by theoretical, empirical and practical factors. For example, it was informed by the purpose of the research, the research situation, the nature of the South Asian population in Edinburgh, my ability to gain access to that population, the small number of similar studies in the field as well as the estimated time and financial costs of conducting the interviews. The following discussion shows that the decision about the final number of cases was based on all the evidence at hand. Where a similar study might have interviewed a smaller number of cases, the discussion weighs up the advantages and disadvantages of a smaller sample in relation to my study. It draws on a number of issues to arise both before the interviews and during my experience of conducting the interviews.

The first stage in determining the number of cases to include was to review some literature on sampling in qualitative research and to apply the lessons learned to the aims of my study. My review showed that in qualitative research, questions about the number of cases to be included in studies are not answered on statistical grounds. As noted above, qualitative samples are purposive and are selected to meet the theoretical needs of the research (Mason, 1996; Arber, 1993; Miles and Huberman, 1984). It showed that in qualitative research, sampling strategy is both informed by theory and used to develop theory (Mason, 1996). In terms of the latter my review emphasised the need to include a range of cases to allow the generation of data to help explore processes, similarities and differences and to test and develop explanations (Mason, 1996) in this case around the issue of South Asian women's access to healthcare.

I then approached the issue of sample size by examining the aims of the study as well as background literature. As noted in chapter 1, the literature on minority ethnic groups and health highlights a lack of empirical studies on minority ethnic groups' healthcare

experiences and perspectives. In addition, it suggests that minority ethnic women have either the same or different experiences of healthcare (Phoenix, 1990). In terms of the current study, this suggested that my approach needed to include a range of South Asian women's voices to examine the heterogeneity of South Asian women's healthcare experiences and perspectives to help understand South Asian women's access to healthcare. My approach also needed to take into account the possibility of heterogeneity in women's experiences and perspectives within each South Asian ethnic category. Further, the number of cases had to provide sufficient diversity of experience and perception whilst retaining the depth of information gained from women's accounts. As noted above, I targeted the range of cases to be included in order to maximise the depth of data gained and decided to include the main South Asian ethnic categories present in Edinburgh in equal numbers as well as non-English speaking and English speaking women.

On reflection, in terms of my aim to gain a range of women's healthcare experiences and perspectives, a smaller number of cases might have presented a number of disadvantages. It might have reduced the possibility for variation in the sample in terms of age, ethnic category, lifestage etc. and it might have reduced my ability to cover the range of experiences and perspectives that existed among the final number of women interviewed. It might also have reduced my ability to cover the range of factors and social processes that affect this group's access to healthcare and therefore reduced the sensitivity of the study to South Asian women's healthcare experiences and perspectives. As noted above, the number of cases in qualitative samples aims to maximise the richness of the information gained, a smaller number of cases might have reduced the depth of understanding gained and it might have limited the depth of the analysis (Sudman, 1976).

An alternative way of approaching such a study might have been to concentrate on a smaller number of cases drawn from one South Asian ethnic category. However, this approach was also rejected as extensive background reading had emphasised that there was a dearth of empirical studies focusing on South Asian women's healthcare experiences and perspectives. Further, it was not clear from the existing literature which South Asian ethnic category to choose in order to adopt such an approach.

The second stage in determining the number of cases included in my study was to examine the small number of qualitative studies in the field and the sampling strategies taken. Given that qualitative studies in the field were relatively new, I also found it useful to talk to others

working in the area for guidance on methodology including sample size. This review showed that a number of important and useful studies had been based on purposively selected samples of between 20 and 40 individuals. For example, Bowes and Domokos (1995a, 1995c, 1993) interviewed 20 South Asian Muslim mainly Pakistani women about their health and healthcare; Donaghy (1994) included interviews with 42 South Asian women in his study on mental health among second generation women; Fenton and Sadiq (1993) included 16 South Asian women in their study on the experience of depression; Currer (1991, 1986) interviewed 47 Pathan women often in group settings, and included in-depth discussions with 17 women about concepts of health and illness behaviour; and Donovan's (1986) study draws on interviews with 30 South Asian and Afro-Caribbean respondents. My review also showed that the decision about the number of cases to include in qualitative work needs to be balanced against the widespread tendency in social science to believe that a large sample guarantees reliable results (Oakley, 1985).

Importantly, this review also alerted me to a range of practical issues when conducting qualitative studies. This was important as the third stage in determining the number of cases to include in the study was influenced by the practicalities of the research situation. These issues cannot be overstated. The number of cases was influenced by my dependence on a number of key informants who put me in touch with potential interviewees. This process affected the time taken to gain access to interviewees and to complete the interviews and therefore affected the number of cases included in the study. Further, the number of cases was affected by the limited resources available for equipment, travel, interpreting and by the fact that I needed to allot a large amount of time to transcribe the interviews fully.

A smaller number of interviews might have presented a number of practical advantages. For example, it might have reduced the costs of interviewing and reduced the amount of time needed to conduct the interviews and to transcribe them. Importantly, it might also have meant that I was 'less dependant' on my key informants and their goodwill. However, it must be stressed that although a smaller number of cases might have been advantageous in terms of helping to free up further time for analysis, this is not to say that all 36 interviews were not analysed in depth and in all their complexity.

These potential advantages of using a smaller number of cases must be seen against my need to gain a range of South Asian women's healthcare perspectives and experiences, my need to gain an information rich sample as well as the practicalities of gaining access to South

Asian women who were willing to be interviewed and the practicalities of data analysis. On reflection, the practicalities of interviewing also meant that I could not predict the richness of the data gained and therefore move toward the decision to concentrate on a smaller number of cases. The lack of financial support to pay for assistance with transcription meant that I transcribed most of the interviews after the interview period and that I was unable to grasp the overall richness of the data until after the interviews were completed and had been transcribed.

Further, in terms of the practicalities of gaining access to potential interviewees, my dependence on snowball sampling methods (see section 2.4), meant that I could not totally direct the characteristics of the women interviewed. On reflection, a smaller number of women contacted using snowballing methodology might have been disadvantageous in that it might have led to the marginalisation of those groups of women who proved harder to contact. Thus my study might have concentrated on women in their thirties and might have excluded women over the age of 50, and it might have concentrated on English speaking women or those women who chose not to be interviewed in a South Asian language. It might also have meant that the experiences and perspectives of Bangladeshi women would not have been represented, as this group proved to be the most difficult to contact. In terms of my broader research training, another disadvantage of using a smaller number of cases might have been that I might not have developed the interviewing skills needed to work alongside interpreters and this might have affected the sensitivity of the approaches taken when conducting these interviews.

In my view, the potential disadvantages of a smaller sample discussed above would have severely restricted the scope of the study and the depth of the analysis as well as the sensitivity of the methodological approaches taken. Overall, where a similar study might have used a different sampling method to gain a smaller sample, snowballing urged me toward a 'larger' rather than a 'smaller' number of cases. That is not to say I had absolutely no control over the number of cases included, rather it shows that the final number of cases included was a negotiation of theoretical and practical factors and that the methodological approach taken was formed in response to the research situation. Simple practical measures helped me to keep track of how far the sample needed to be modified in order to include a range of women. They also helped to keep the sample size down in the face of limited time and resources. 'Stock-taking exercises' (Mason, 1994: 103), including entering the characteristics of the women into a grid (e.g. lifestage, age, length of time in the UK),

helped me not only to record sampling decisions but to think systematically about the approach taken and to take decisions about how to proceed. This practice was particularly important as I tried not to overburden each key informant who put me in contact with potential interviewees.

My experience and the methodological steps taken have a number of implications for other qualitative studies. These are that studies need to weigh up a number of theoretical, empirical and practical factors and that these must be balanced against the need to carry out the interviews efficiently, the need to leave ample time for analysis and writing-up as well as the time and resources available to a project. Although a smaller number of cases might have presented a number of advantages, it is important to stress that such a methodological step might have presented a number of disadvantages. In particular, it might have reduced the scope of the study in terms of the range of women included and the range of healthcare experiences and perspectives represented. It might also have had implications for the sensitivity of the methodological steps taken. In the end it was perhaps more important to develop a methodology that was sensitive to the perspectives and experiences of South Asian women and allowed me to interview a range of women and to gain an information rich sample, than to achieve a certain sample size.

Having identified the characteristics of the women I needed to speak to in order to examine South Asian women's access to healthcare and discussed the issue of sample size, the next question to be addressed was how to secure access to the women I wanted to interview.

2.4 Gaining access to interviewees

This section discusses the process of gaining access to potential interviewees. My discussion includes debates in the methodological literature and an analysis of sampling methodologies used in other studies. It shows that the process of gaining access to women was influenced by the practicalities of doing research and by the research setting in Edinburgh. According to Hammersley and Atkinson (1983: 53):

'...[The] Problem of gaining access to data is particularly serious...since one is operating in settings where the researcher generally has little power and people have pressing concerns of their own that give them little reason to co-operate.'

My approach was also influenced by other studies on minority ethnic groups and healthcare which had described problems in gaining access to those they wished to study (Swindon CHC, 1993; Pilgrim *et al.*, 1993; Thorogood, 1988; Currer, 1986; Donovan, 1986). The women I talked to were accessed via a network of personal contacts established in the year preceding the interview period.

Snowballing is often used to obtain a sample where there is no adequate list which may be used as a sampling frame (Arber, 1993). It is a method useful for obtaining samples of numerically small groups and for targeting members involved in networks. Contact is made with a member of the population of interest who becomes a gateway to others. S/he is then asked whether s/he knows anyone else with the requisite characteristics to help with the study. The decision to use such a sampling method was based on all the evidence at hand. In practice it meant that gaining access to women was increasingly defined by the women I was introduced to and by information gained from key informants. Before outlining the benefits and limitations of gaining access to potential informants in this way, it is necessary to consider other studies which have used different sampling approaches.

Other approaches to gain access

Other studies on minority ethnic groups have used 'comprehensive' sampling frames gained from population lists, such as the Census, Electoral Roll, Health Board and GP lists or maternity records, to gain a number of potential interviewees (e.g. Ecob and Williams, 1991; McAvoy, 1989). A number of studies focusing on South Asian populations have identified potential respondents on the basis of surnames and selected potential respondents on the basis of informed estimations (McAvoy, 1989). Other sampling methods have focused on minority ethnic population concentrations (Bowes and Domokos, personal communication; Ecob and Williams, 1991) or have identified potential interviewees by sight in health service settings (Thorogood, 1989, 1988). These approaches were rejected for a number of reasons.

Firstly, such lists may not be comprehensive. For example, studies have questioned the rates of registration of minority ethnic groups on lists such as the electoral roll (Pilgrim *et al.*, 1993), others have questioned the quality of primary care registers (Nicholl *et al.*, 1986), and their use in mobile populations (Ecob and Williams, 1991).

Secondly, name sampling or sampling by sight was considered to be inadequate to my needs and unnecessarily time consuming. Name sampling techniques are generally more

appropriate to larger scale studies and names are not good surrogates when a sample size is small. For example, Johnson *et al.*'s (1983) study in Birmingham started with 6122 names from GP lists, and a subsequent screening survey gave a sub-sample of 2161; and Bhopal's (1986a) study in Glasgow used GP registers to yield 413 names from which 100 were selected and 65 people were interviewed.

Thirdly, sampling using lists was judged to be unreliable. For example, names originating in the Indian subcontinent are not an accurate representation of minority ethnic origin. My own name, for example, could be either Indian or British. Other studies, including Pilgrim *et al.* (1993), describe problems in distinguishing between Bangladeshi and Pakistani Muslim names. In addition, it was anticipated that I might face difficulties contacting South Asian women given that women's names may be changed after marriage (McFarland *et al.*, 1989; Nicholl *et al.*, 1986).

Fourthly, sampling using population lists was rejected on practical grounds. I anticipated that such approaches would be disproportionately time consuming. Furthermore, the use of population registers such as GP lists would require the negotiation of ethics committees or GP surgeries. Further, random sampling by address on the electoral roll would have become prohibitively expensive. The use of registers and name sampling would have meant that I was reliant on another person to help identify potential interviewees. This practice would also have raised a number of questions about the confidentiality and privacy of potential interviewees. I also anticipated that these barriers might bring high refusal rates and a lower completion of interviews.

Finally, the use of population lists was rejected as it did not fit the study design. Methods of random sampling by address or electoral roll may not have guaranteed finding women from four South Asian categories across the age range. In addition, I needed to include women with a range of healthcare experiences. The use of GP lists would have limited the range of GP experiences to a particular practice. I also did not want to be identified with health service providers. I felt that this might affect the responses gained. Snowballing was the only way to achieve the sampling criteria 'efficiently' given the research setting and the time and resources available.

Stages of gaining access to interviewees

Snowballing took place in two stages: initial groundwork and approaching interviewees. The first stage started in the women’s voluntary sector which provides services for a large number of minority ethnic women in Edinburgh. Such an approach seems justified by Smith’s (1991) Scottish wide study of minority ethnic groups which indicates the extensive use of community institutions by minority ethnic groups.

I targeted nine groups (of which six were successful) in the voluntary sector catering for a range of different minority ethnic groups and ages. This led me to contact religious institutions such as the Mandir (Hindu temple) and the Gurdwara (Sikh temple) along with other official gatekeepers. The latter included the Race Equality Unit of Lothian Council and the Commission for Racial Equality, as well as a number of other researchers in related areas. I outlined the project, its aims and organisation. These sources provided guidance and suggestions for further contacts to assist my study.

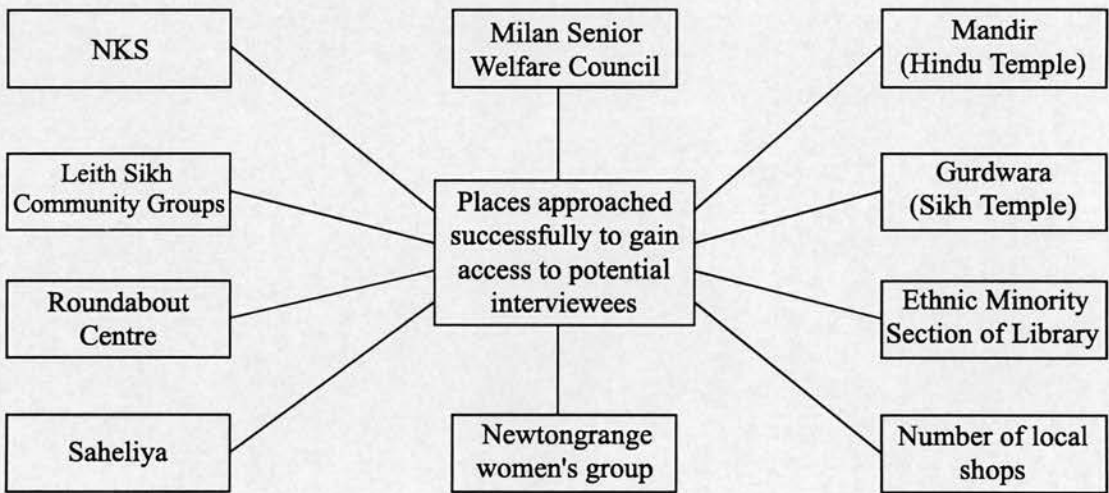


Figure 2.2 Places approached successfully to gain access to potential interviewees

Access to women was negotiated with a variety of groups only after at least one meeting or informal visit. Following a letter, seven meetings were arranged with a variety of voluntary groups (one meeting proved unsuccessful). From there I found a number of potential interviewees and added to my list of contacts or key informants who advised me and assisted access to potential interviewees. A list of groups assisting with the project is shown in Figure 2.2. Further assistance was gained from others who I had met whilst living in Edinburgh and by a contact in the minority ethnic section of a Public Library based in Leith.

The latter is the second most used library by minority ethnic groups in Edinburgh (Councillors Research Unit, 1992). A range of key informants and institutions meant that I covered a wide range of the city and ensured that the women had a variety of healthcare experiences and used a number of health services.

The second stage was approaching interviewees. Potential interviewees were approached in three ways. Firstly, by a number of different key informants I had met through voluntary groups and key contacts, secondly, through personal contacts met through interviews, or thirdly, by me directly, through voluntary and crèche work and by attending health sessions at some of the groups.

The flexibility of snowballing approaches gave a variety of other benefits. Initial access to the women informed the research design. This phase of the study was akin to Fenton and Poonia's (1988) familiarisation phase which helped me to observe the scene and to ask questions. This helped to establish a degree of shared knowledge and agreement about the research and my involvement with it. This stage gave invaluable insight into a number of issues that are not addressed in the literature. For example, I was able to increase my understanding of factors that might affect South Asian women's access to healthcare. It helped me to try out and to refine my interview schedule and gave me ideas for analysis. Local advice gained from key informants was also invaluable to my study. They indicated potential sources of interviewees, provided information about the South Asian groups in Edinburgh and alerted me to potential problems that I might face.

The familiarisation phase also allowed me to ascertain the best ways of approaching potential interviewees. Access through the voluntary sector allowed me some contact with a range of women, including some of those I was to interview, before the interview period began. This assisted the smooth running of the study, for example by alerting me to the resources that I might need during the interviews.

In general, different approaches needed to be taken with each South Asian ethnic category. My initial groundwork showed that some of the voluntary groups were used more by women from particular South Asian ethnic categories than others. This allowed me to plan ahead. In the main, Indian and Bangladeshi women proved to be most difficult to contact through the voluntary sector alone. This was unsurprising as Bangladeshis are by far the smallest of the groups in Scotland (Table 2.2) and Indian groups tend to be more dispersed in the city. Many of the Indian women were contacted via the Mandir and the Bangladeshi women were

contacted through one particular key informant who also acted as interpreter/advocate in a number of these interviews. Without her knowledge and patience, access to Bangladeshi women would not have been possible and the study would have been incomplete. Problems of accessing Bangladeshi women are also seen in other recent studies on minority ethnic groups and health both inside and outside Edinburgh (e.g. Fenton *et al.*, 1995; Pilgrim *et al.*, 1993; Donaghy, personal communication).

Advantages of snowballing

In terms of approaching interviewees, snowballing and gaining access to women through a third party gave a number of advantages. Snowballing meant that the women were contacted through an individual, for example a community worker, who was known to them, which gave the study and myself some degree of legitimisation. It also ensured that women were approached in a 'non-threatening way'. The community worker explained the aims of the study, ensured confidentiality and let the women think about their decision to take part. Approaches through a known third party also helped to tackle situations that could render interviewees vulnerable to exploitation (Finch, 1984). This practice helped to avoid a number of anticipated problems, and to give space to interviewees who were unsure or sceptical about the intentions of the researcher or were concerned about what I might do with the information. In addition, this type of approach helped to ensure confidentiality where I was unknown and a newcomer to Edinburgh. Snowballing, therefore, enabled a degree of shared knowledge and agreement about the purpose of research.

After contact through a third party, either a key informant or another interviewee, I telephoned the woman with a checklist of points about the study. In doing so I introduced myself and outlined the general aims of the study and the length of time the process might take. I also specified where I had obtained the woman's name and phone number and guaranteed confidentiality. This approach proved successful. In some cases introductions took place through the key informant only. Sometimes I had met the woman before the interview. In these cases formal introductions were not needed. In other cases, where the woman felt it was necessary, I posted a prepared sheet of information about the study before the interview. Unfortunately, the resources of the project did not give financial support for any information that was sent out to be translated. My applications for assistance, which included costings and an agreement from Lothian Interpreting and Translation Service to help me, were unsuccessful.

Snowballing approaches also assisted the relationships established with the women and the flow of the interviews. My study supports Bowes and Domokos' (1996) impression that snowballing increased trust and rapport in the interviews. Initial approaches to the women aimed to build some degree of trust and to establish the legitimacy of my study. Snowballing assisted in minimising barriers between the interviewee and the interviewer. It also meant that a degree of mutuality formed the starting point of each interview.

Finally, the initial access phase also put me in touch with potential interpreters/advocates to assist with the study. This gave a number of advantages besides allowing access to those women with little or no English given my lack of knowledge of South Asian languages. The interpreters were known and trusted by the women I was to interview. One interview was carried out through a daughter-in-law, at the woman's request. The other two interpreters used their language skills in their own work. Both had undertaken previous work as interpreters in health services or other institutions, such as the legal system. Further discussion about the use of interpreters is given in section 2.8.

Disadvantages posed by snowballing

Snowballing also poses a number of disadvantages. Firstly, snowballing can only be used to target those involved in networks. I responded to this problem by minimising the chance of being confined to a single network by contacting a number of key informants both inside and outside the voluntary sector.

Secondly, snowballing raised a number of questions about the selectivity of the women I spoke to. The questions remained, were the women selected on the basis of some unspoken criteria? Were some women sampled out? Did the sample include those with the 'best' relationships with voluntary groups? These questions are very difficult to answer. My sample includes women with a range of experiences and characteristics and those who attend and do not attend voluntary groups. This was part of the natural progression of my project. As more women were contacted and the research got underway, the network grew. This posed another question, did access to healthcare vary between attenders and non-attenders of voluntary groups? A number of factors make this question difficult to answer. Firstly, the range of organisations attended by the women include those with different remits, for example a focus on a single issue such as mental health or alternatively broad based provision such as community social groups, which give health, welfare, legal and practical support. Secondly, my sample also includes women who use organisations

regularly and sporadically. This is characteristic of the network membership of such groups which comprise both a regular and a floating membership (i.e. those with only occasional contact with a group), alongside a web of contacts outside the group (Wardhaugh, 1991). Close scrutiny of the transcripts shows no distinct difference in the accounts of attenders and non-attenders.

Thirdly, snowballing meant that it was difficult to be prescriptive in terms of the social characteristics of the women interviewed. I responded to this problem by setting out my needs at the start of the project. The process of sampling was ongoing. Constant ‘stock-taking exercises’ (Mason, 1995: 103) meant that as clusters appeared, I emphasised that different women needed to be included. However, I was unable to direct the age of the interviewees totally or to ascertain the generation or socio-economic status of each woman before interviewing (see section 2.5). In addition, whilst I aimed to include those with language problems, such an approach may have meant that gaining access to potential interviewees was slightly restricted to women who could speak English. As noted above, I am unable to speak any South Asian language.

Having decided to speak to women in a range of different South Asian categories, with different healthcare experiences across the age range. The next section outlines the socio-economic characteristics of the women interviewed.

2.5 The study: A socio-biographical profile of the respondents

This section summarises the biographical information gained from women at the end of each interview. It illustrates the range of women interviewed in terms of age, family composition and education among other variables. The range of healthcare experiences and services used are contained in the empirical chapters. Table 2.3 summarises the ages of the informants according to South Asian ethnic category.

Age range ints. (yrs)	Pakistani	Sikh	Indian	B/deshi	Total
20s-30	4	2	1	4	11
30s-40	3	4	5	2	14
40s-50	1	2	1	1	5
50+	1	1	2	2	6

Table 2.3 Age range of the interviewees

As noted above, I was unable to control the age of the women interviewed. As a result an element of clustering is seen in the age ranges and lifestages of the women interviewed. Most women were in their twenties and thirties, were married and were mothers (see below). This is in accordance with the 1991 Census which shows that the majority of South Asian women over 15 are concentrated in the 25-44 age group (Table 2.4).

Women of South Asian ethnic category	Indian	Pakistani	B/deshi
% 16-24	15.4	18.0	18.5
% 25-44	35.4	27.1	23.1
% 45-59	13.3	9.2	9.0
% pensionable age	6.6	2.9	1.6
Median age in years	27.9	19.7	16.9

Source: Census 1991 in Owen (1994)

Table 2.4 Age of South Asian women in the UK

Such clustering has the potential to increase understandings of South Asian women's access to healthcare. This age group is the main childbearing age span, therefore, there is more contact with health services. Also there might be greater personal awareness of healthcare. Chapter 1 noted that women occupy a pivotal role as providers of family healthcare. In this age group personal knowledge of women's health might increase, as might an awareness of gynaecological problems. In addition, women's experience of screening is heightened, as good maternity care should provide a screening programme for women.

As noted above, my sample may have been slightly restricted to those who had a good command of English language. Table 2.5 shows that about a third of the interviews were carried out using interpreters. Some women, despite English language difficulties said that they did not need anyone to interpret. Other women requested an interpreter as they were unable, unwilling or lacked confidence, to speak English (section 2.8).

Int. type:	Pakistani	Sikh	Indian	B/deshi	Total
No. with interpreter	3	1	1	8	13
No. without interpreter	6	8	8	1	23

Table 2.5 Number of interviews conducted with an interpreter

The biographies of the women show that all but five of the women were born in the Indian subcontinent. Two were born in Scotland, though not in Edinburgh, and three were born in England. Thirty five women's parents were born in the Indian subcontinent (one woman's parents were born in the subcontinent and in Kenya).

The women had come to Edinburgh at different times. All but one had settled in Edinburgh after marriage. The women included long term residents and those resident in Edinburgh for a shorter time. Five women had been in Edinburgh for less than five years, 10 women for between five and 10 years, 14 women for between 10 and 20 years and seven women for over 20 years. Seventeen women had lived in England for a considerable length of time (over two months after arrival in the UK), seven of these women had spent much of their childhood in England. Three had lived outside Lothian in other parts of Scotland. One was born in the Indian subcontinent but had grown up in Scotland. All but seven women had relatives in other parts of the UK, though this did not necessarily include their own birth family.

All but one woman had had some form of education. Nineteen women were educated in the Indian subcontinent, five in both the Indian subcontinent and the UK and 10 in the UK alone. Table 2.6 shows the number of women in paid work outside the home and in education. The Bangladeshi women were less likely to be in paid employment than the Indian or Pakistani women. Three women were in part-time work. These findings align with the 1991 Census which shows that South Asian women (defined as Indian, Pakistani and Bangladeshi) are less likely to be in part-time work than white women and that although Indian women have the highest rate of economic activity among South Asian women, the unemployment rate among Indian women is twice as high as for white women and even higher among Pakistani and Bangladeshi women (Owen, 1994).

Employment type	Pakistani	Sikh	Indian	Bangladeshi	Total
Part time	0	1	1	1	3
Full time	0	1	1	0	2
Family business	1	1	4	0	6
In Education	1	1	0	0	2

Table 2.6 Employment outside the home/education profiles of the women interviewed

All but two women were mothers and at the time of interview one woman was pregnant with her first child. Table 2.7 shows that most had school or preschool aged children.

The profiles of the women interviewed show variation in terms of family size and structure. Twenty seven women lived in single households, that is households comprising the woman, her husband and all or some of their children. Six women lived in what might be called an extended household composed of the woman's generation plus a younger generation [3

women] or an older generation [2 women] or both [1 woman]. One woman lived alone since she had been widowed and another lived just with her husband.

Category of child	Pakistani	Sikh	Indian	B/deshi	Total
Preschool aged	2	1	1	1	5
School aged	3	2	5	2	12
Preschool and school aged children	3	3	0	3	9
Older dependant children	1	2	1	0	4
Non-dependant children	0	1	1	2	4
No children	1	0	1	0	2
Total with children	8	9	8	9	34

NB Several women had more than one child, this is included in the totals

Table 2.7 No. of women with children

The sample also includes women in a range of different socio-economic circumstances (see appendix 1), it is, however, difficult to group the respondents according to socio-economic group and therefore to discuss the effects of socio-economic group on access to healthcare. Socio-economic group is a product of the position occupied in the country of origin, residence in the UK and the British class system (Bhachu, 1985). The majority of South Asians occupy low socio-economic status (Bhachu, 1985) and are concentrated among unskilled and semi-skilled manual occupations. In my study the identification of socio-economic status is complicated by the fact that many of the women were not in paid work outside the home. Often housing is used as a proxy for socio-economic status, however, for minority ethnic groups it is not a good proxy as minority ethnic groups' housing patterns are complicated by a number of choices and constraints (Bowes, Dar and Sim, 1995). In my study the women also lived in a range of housing types and tenures. This again makes it difficult to place the women interviewed according to socio-economic group. Table 2.8 shows that most of the women owned their own homes reflecting the high level of home ownership among South Asians (see Owen, 1994 for a review of the differences in housing tenure among ethnic categories).

Tenure type	Pakistani	Sikh	Indian	B/deshi	Total
Owned	8	5	8	6	27
Owned by family	1	3	1	1	6
Private rent	0	0	0	2	2
Council rent	0	1	0	0	1

NB. Owned by family = owned or being bought by a family member other than a partner

Table 2.8 Housing tenure of the interviewees

Having defined my sample I will now focus on the techniques used to interview the women.

2.6 Semi-structured interviews

Approaches considered

There are a number of different qualitative techniques and approaches and 'few clearly agreed rules' (Richards and Richards, 1994: 149). The choice of technique depends on its relevance to a project and the purpose of the resultant data (Dey, 1993). In my study the research instrument used has to be able to collect data on South Asian women's experiences and perceptions in three different healthcare arenas. Semi-structured interviews were chosen as the best way forward. This section describes the design considerations and the interview schedule used.

Semi-structured interviews allow the researcher to gather information in the words of the researched rather than those of the researcher (Reinharz, 1992). They assume the interviewer has a specific issue to explore, but does not have a strict protocol to follow nor predefined answers (Lofland and Lofland, 1984). I had a specific issue to explore but I did not claim to know all the right or relevant questions or answers. Open-ended questions formed the backbone of the interview from which to deviate from and return to. The interviews were flexible enough to cover areas I wanted to address directly and to give space to the women to describe their healthcare perspectives and experiences that were not on the schedule, in ways that I hoped were satisfying to the women themselves.

This type of interview was chosen for a number of reasons. Firstly, there is some evidence that approaches involving standardised questions may fail to collect the views of minority ethnic women. Cartwright's (1987) postal questionnaire study on recent mothers achieved a 42% response rate from Asian born women and Garcia's (1993) study of consumer views of maternity services which stresses quantitative research instruments, also raises the issue of low responses from minority ethnic groups. A small number of semi-structured interviews gave the chance to engage with interviewees giving a forum for their own views and for them to define issues in a number of areas. Semi-structured interviews meant that the interviews became a dialogue rather than a monologue. This allowed me to move away from 'short superficial interviews' (Fenton and Sadiq, 1993: 8) of quick questions and answers.

Secondly, semi-structured interviews helped me to avoid predefined research questions and categories of response. This was in line with the aims of my study. Chapter 1 showed that

the definition of research questions in the area of minority ethnic groups and health is especially sensitive and criticised approaches that have perpetuated stereotyped research agendas.

Thirdly, semi-structured interviews were chosen because I felt that the type of research instrument used would influence the responses gained. There are different forms of interviewing, each is designed to focus on a particular task and exhibits a different degree of standardisation. Given the aims of my study neither a structured nor an unstructured research instrument was considered suitable.

Unstructured interviews are open-ended and employ non-standardised questions. They assume that the researcher does not know what questions to ask but that appropriate questions will emerge. Although this would have allowed me to uncover women's perceptions and experiences in detail and allowed interviewees to talk about the subject in their own 'frame of reference', I was specifically concerned with collecting data in three healthcare arenas. I needed to set the frame of reference in the interviews whilst remaining open to and facilitating emergent issues.

At the other end of the interview scale, structured interviews assume that the researcher already knows what kinds of categories the interview will uncover. They aim to elicit 'choices between alternative answers to predefined questions' (Lofland and Lofland, 1984: 12). The questions used are assumed to be unambiguous and designed to provoke discrete and unqualified replies. In terms of my study I was unaware of the issues that would be uncovered in the interviews and wanted to explore the depth and detail of women's accounts. I judged that structured interviews would allow little room for the women to express their own opinions in the way they wished (May, 1993).

This issue is addressed by Bowes and Domokos' (1996) evaluation of structured quantifiable approaches. They conclude that they do not address the negotiation of power in interviews in a number of ways. Firstly, they show that direct questions may signal the superiority and possession of knowledge by the interviewer resulting in the interviewees' knowledge being devalued. Secondly, in structured interviews the capacity to shape and control interviews rests more with the interviewer than with the interviewee. Thirdly, structured approaches may lead to a number of responses that negate the depth of information that might otherwise be gained. Respondents may feel that they need to offer the 'correct answer' by providing information that they believe the interviewer wants to

hear. They may also offer safer answers such as 'don't know' or curtail their responses. Although this may satisfy the interviewer it may act to obscure the interviewees' perspectives. All these reactions involve the researcher exercising power over the interviewee, the result being that the researcher does not get the information that is desired. On balance, such a 'closed' approach to questioning did not align with the aims of my study, the need for user views or the need for a broader conceptualisation of access to healthcare.

The interview schedule

My semi-structured interview schedule was developed and reviewed with time and experience. Transcription and analysis of four pilot interviews allowed me to examine and improve the questioning process and to shape the final version of the schedule (see appendix 2). After the preliminary interviews were reviewed I judged that they did not differ in quality from the others and so included them in the study. Piloting gave insight into responses, the interview process and the time required. As a result, single interviews were favoured for a number of practical reasons. Firstly, I anticipated problems recontacting women. Secondly, constraints on the time and resources available to the project meant that I was unable to pay for interpreters a second time. I also felt that it was unfair to restrict second interviews to English speakers, this would have excluded most Bangladeshi women and a number of Pakistani women. Thirdly, restrictions of the project's resources meant that I would have been unable to pay for interviews to be transcribed in time for second interviews. Figure 2.3 shows the structure of the schedule used.

The sequencing of questions was an important design consideration. The schedule was divided into five sections. It started with information that might be more easily ascertained from women in their everyday lives. Initial questions set the tone of questioning and aimed to encourage women to describe their thoughts and feelings in detail whilst demonstrating my interest in their views and experiences. Most women seemed comfortable with this, only one woman paused, I suspect that she was expecting more structured, quick response questions. In this case I turned the tape recorder off, we chatted and discussed further what the interview would involve.

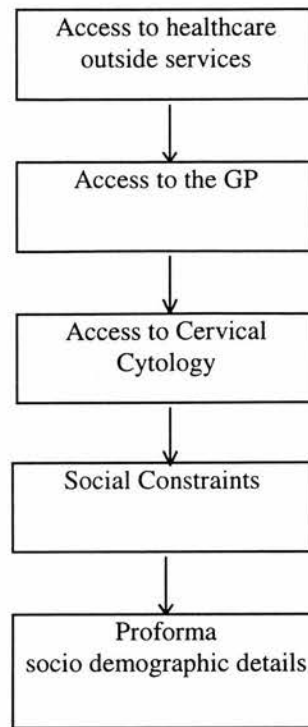


Figure 2.3 Structure of the interview schedule

I began simply by asking women about their own health and healthcare experiences outside services. I then asked about health services and moved from questions about the GP, a more general service to a more specific service, cervical cytology. All sections focused on pathways into healthcare and healthcare attitudes and actions. As noted in chapter 1, use of healthcare outside services has an everyday quality, use of the GP is episodic and use of cervical cytology is periodic. The questions had to capture ideas about access to these different types of healthcare.

Questions about access to the GP and access to healthcare outside services involved more general questions about experiences and views, whereas those about cervical cytology focused on women's first and last attendance. The challenge was to use women's first and last experiences as a gateway to more general views and experiences. The first experience of screening was thought to be significant in order to understand subsequent uptake and to provide a context in which to situate women's perceptions and experiences of cervical cytology. I felt that both these screening episodes might be more easily recalled, although the questions gave leeway for women to talk about other episodes. Finally, the schedule moved on to more abstract questions about social constraints and attitudes to the Health Service. Quantitative socio-demographic, personal biographical and health service

information was left until the end, as I did not want to set the tone of the interview with predefined short answer questions.

Open-ended questions were prepared along with prompts that were used to gain more detail or clarification. These were added to in the course of the interview conversations. In practice, the actual instrument was used less and less as the interviews progressed. Topics were covered in the order that they were raised by the women according to the depth and pace that they wanted. The majority of interviews included most of the topics and always had the potential to include issues outside my predefined areas. One of the women was not asked about cervical cytology. The interpreter and I decided it was inappropriate to include these questions due to the almost continuous presence of her husband, though we found out that she had never been tested.

For rigour and ease of analysis all interviews were taped. They lasted between one hour and up to four hours. More than 70 hours of tape were then fully transcribed. On contacting the women, I or a key informant explained that I would like to use a tape recorder. If anyone felt uneasy about the tape recorder in the interview itself I explained that it was to ensure that views and experiences were properly described but that I would be happy to take notes instead. None of the women refused to be taped.

The structure, wording and practice of questioning enhanced the interaction in the interviews in a number of ways. Firstly, the content and the language was negotiated making the interviews flow better. In practice I 'hooked' into the women's responses and asked questions in predefined areas. These practices aimed to limit misinterpretation and to allow the significance of women's responses to be understood. Secondly, I took steps to ensure that the actual questions asked contained neither difficult, technical nor emotive terms. They were asked simply, and one at a time. Thirdly, I avoided asking questions that suggested an appropriate response and which drew on assumptions about the healthcare practices of South Asian women. Fourthly, interaction was enhanced by greater familiarity and confidence on the part of the researcher. Fifthly, the flexibility of the approach allowed me to explain questions when asked or when a woman seemed unclear. In some cases the answers given did not correspond to the question. In such instances the question was asked in a different way later in the interview. This practice helped to avoid any discomfort caused to the women and to avoid limiting the interview flow. All five factors were all the

more important when talking to women with limited English or when assisted by interpreters (section 2.8).

The nature of the research instrument used meant that the women were able to shape the interviews to some degree and gain some control over the interview situation. As noted above, the women determined the ordering of topics and the depth in which they were discussed. Although an imbalance of power in the interview situation is generally inevitable I tried to negotiate power in a number of ways. Working on my own or with an interpreter the need to be flexible in approach was always stressed. Most interviews took place in familiar surroundings at times specified by the women. The interviewees determined not only whether I was to be granted access, but when and where the interview should occur and in what room. In all cases I was invited as a guest. On a number of occasions the interview took place in two visits so avoiding disruption to the women's routines and obligations. On other occasions the interviews were suspended in order for women to fulfil obligations. For example, one woman left me in her home with her son until she returned from a prearranged engagement to complete the interview. On another occasion a woman was getting ready to go out. I helped her to pin part of her *salwar kameez* (Punjabi dress, suit with trousers) whilst she answered some questions. In a number of interviews, at the interviewees initiative, we sat and chatted about the women's concerns and experiences, ideas about family, food, visiting the Indian subcontinent, about life events as well as about health and social services.

I believe that my own relative disempowerment in the interviews added to the depth of the information gained. Although I had designed and controlled the study this was in part balanced by the scope given to the women to shape the interviews and by what I feel to be measures to enhance my sensitivity to interviewee needs during the interview time. However, the boundaries of the interview process remained essentially controlled by the researcher (Bowes and Domokos, 1996) who had designed the schedule. The research process was quite different when conducting interviews with interpreters, this is considered below and in section 2.8.2.

Practical issues relating to the use of interpreters

There is little discussion of the use of interpreters in social research with the exception of work by Bowes and Domokos (1996), Edwards (1995) and Freed (1988). This is surprising, given the increasing amount of research focusing on minority ethnic groups. In the health

field, debates on the use of interpreters have concentrated on the preparation of standardised research questions which retain their meaning on translation and which are meaningful for minority ethnic groups (Bhopal, 1992). Some work also touches on the use of interpreters by the users of health services (e.g. Hornberger *et al.*, 1996; Pershad and Tyrrel, 1995; Ahmad *et al.*, 1991b; Wright, 1983). Less has been written, however, about the experience of working with interpreters either from the point of view of interpreter alongside a researcher or vice versa, or as a bilingual researcher. Further, little has been written about the interaction in the research situation when working with interpreters (but see Bowes and Domokos, 1996 and section 2.8.2). A number of factors may have impeded the process of learning from work conducted alongside interpreters. Firstly, it is more common for minority ethnic groups to be seen as the subjects of research (Stanfield, 1994) than participating in research. Few researchers are from minority ethnic groups (Rhodes, 1994). Minority ethnic groups are still under-represented in research activity (Wrench and Reid, 1990). And secondly, work with interpreters is often considered not out of choice, but because of a lack of alternatives (Fuller and Toon, 1988).

In the current study, work alongside interpreters presented a number of advantages. This practice allowed me to broaden the scope of the study by including the perspectives and experiences of non-English speaking women. It also enhanced the sensitivity of the research process by catering for those who felt more comfortable being interviewed in their chosen South Asian language. The following discussion examines the practicalities of working with interpreters - from recruiting, to the provision of resources for such work, to working alongside interpreters. It includes a number of lessons learned and implications for further studies. Section 2.8.2 goes on to discuss the dynamics of working with interpreters as an active process. My experience has shown that working with interpreters is not a straightforward process. It is argued that interpreters greatly enhanced, and played a positive role in, the research process.

The first stage was to find out all I could about working with interpreters. I therefore took advice from researchers who had employed interpreters in their own work, either as community interviewers or in combination with a researcher. I also talked to linkworkers in a General Practice in Bristol as well as to potential interpreters in Edinburgh. This raised my awareness of the research situation and potential issues and problems in the research process (see section 2.8.2). The practical lessons learned in terms of the resources and time required to conduct interviews alongside interpreters were invaluable and informed later

discussions with potential interpreters. For example, these discussions emphasised the need to ensure confidentiality and that I should aim to use women interpreters. Such discussions stressed that the latter would assist access to potential interviewees and add to the quality of the interviewing environment by helping to increase the acceptability of the research situation for the women interviewed and by helping them to feel less constrained in discussing sensitive topics and personal details, including cervical cytology. This reinforces other work which argues that using women to interview women makes the situation less threatening (Arber, 1993) and work on interpreters which stresses that interpreters should be the same sex as the interviewee and have a non-familial relationship with the interviewee (Edwards, 1995).

The next stage was to approach and recruit interpreters. Ideas about potential sources of interpreters were formed during my contact with the voluntary sector in the city, other researchers in the field plus other key informants including the Race Equality Unit based at Lothian District Council. These sources were of particular importance given the lack of permanent in-house interpreters in health services (Edwards, 1995).

The resources available to the study meant that a number of sources were deemed outside the reach of the project. Trained interpreters and qualified professionals are often considered to be the most effective way of avoiding many potential problems including confidentiality and misrepresentation (Edwards, 1995). It is unfortunate that formal requests for funding for interpreters both to the Research Council and the University were unsuccessful. A small grant was, however, obtained from my department for this purpose. Despite this, the sum in question meant that some sources of interpreters such as Lothian Interpreting and Translation Service (LITS), which provides interpreters on a sessional basis, were not options open to the project. Further, back translation, where an independent interpreter checks the accuracy of what is translated in an interview, was also outwith the resources of the study as it would have been a lengthy and costly process. It must be noted that the use of professional interpreters has been debated and presents advantages and disadvantages. Edwards (1995) for example, argues that one disadvantage is that outside interpreters may need to spend time establishing their credibility with interviewees/clients. On the other hand one advantage is that interviewees are not dependent on maintaining a good relationship with a professional interpreter. This is important. A family member enlisted to help with interpreting might themselves be affected by the research process.

The funding status of the project and the resources available to it meant that once again the voluntary sector assumed an important role in providing sources of interpreters. It must be emphasised that the scope of the project would have substantially reduced without support from this sector and the interpreters who assisted with the interviews. As noted above, I was particularly lucky in that my search for information about work alongside interpreters described above, also led me to potential sources of help with interpreting and that the first two interpreters to be approached agreed to assist with the study. Both interpreters spoke English and at least one South Asian language/dialect and used their language skills in their paid employment. I had met both women before and this formed the starting point of one to one discussions which moved on to address general issues including what the work would involve, how it would be organised, the timing of the interviews and payment.

The recruitment of interpreters was based on the need to cover the range of languages that might be spoken by potential interviewees. However, the precise number of interviews that needed to be conducted with interpreters could not be pre-empted for a number of reasons. Firstly, the snowballing methodology employed meant that I could not predict what kinds of women would be interviewed. Secondly, competence in English language cannot be predicted by indicators such as length of time in Britain or ethnic category. Although studies have found differences in English language ability by South Asian ethnic category and by gender, there is much homogeneity of life experience within ethnic categories (see Edwards, 1995 and Section 2.3). And finally, it was impossible to predict women's choice of language in the interviews.

My experience raises a number of implications for future research focusing on or involving groups whose first language is not English. Firstly, ample resources for interpreting need to be costed into project outlines. Research funders in particular should be aware of the cost implications of the projects that they choose to support. In the current study, the Research Council did not make any provision for financial support over and above 'Research Costs' given to my department. In turn, research funders should not underestimate the resources required when working with interpreters. In order to gain maximum benefit, such resources should include money for phone-calls and for travel both to and from the place of interview and for planning the interviews with interpreters (see later). In addition, in the current study some women required second interviews. This must also be allowed for in research planning.

I tried to maximise the resources available to the study as much as possible and was particularly fortunate in that the interpreters' commitment and time dedicated to the project was immense and this certainly contributed to the successful management and timely completion of the project. Payment was agreed for each completed interview. Final payments were made after all the interviews were completed. This arrangement was unfortunate but was necessitated by funding restrictions and by my inability to contribute financially. One implication in terms of future work in the area is that researchers and funders must recognise that interpreting is a skilled job, and that it must be paid properly. This is of wider importance when we consider that the ability to communicate non-western languages is less valued and less likely to be perceived as a useful skill than competence in European languages for example (Edwards, 1995). In the current study the only alternative to working with interpreters was to reduce the number of non-English speaking women interviewed. However, such an act was seen to be short-sighted and would have severely restricted the scope of the study. As indicated in section 2.3, it was judged that non-English speaking women might experience the poorest access to healthcare and that their experience might differ in some ways from English speaking South Asian women.

The next stage was to plan and carry out a number of interviews alongside interpreters. One of the lessons learned from this work is the need to incorporate time for thorough groundwork, briefing and reflection on the research process within the timescale of projects involving interpreters. In the current study, it was useful to do this both before interviews commenced and after carrying out a small number of interviews. This time was both purposeful and informative.

Before the interviews it allowed the interpreter and myself to examine the role of the interpreter, and to establish a shared understanding about the aims of the project. It allowed us to discuss the process of conducting interviews, in particular the need to leave space for the women to talk as well as the use of prompts stemming from what the women said themselves and the research questions used. We took time to discuss issues that might arise during the interviews including the issue of confidentiality, the use of tape recorders and the seating positions of all parties in the interviews. In terms of the latter we decided that this should be up to the woman interviewed. This time also gave space to discuss the interview schedule and to incorporate subtle changes to it, including the interpreters' concerns about South Asian women's access to healthcare. This included some discussion about the wording and meaning of some questions, an examination of the structure and format of the

interviews and agreement in terms of embedding potentially sensitive personal questions in more general ones. For example, questions about whether a woman had had a smear test or whether a woman had experienced an abnormal smear were embedded in general questioning about women's attitudes to testing and their views about cervical cytology. In retrospect, this time was especially important as the resources available did not allow for the study to be piloted with an interpreter. However, it meant that my experience of piloting could be fed into the discussion.

After the interviews, Edwards (1995) recommends a debriefing process. In the current study, frequent telephone calls and the time spent talking on the way back from the interviews were important in this respect, although it was not possible to talk after every interview due to time constraints and other responsibilities. This practice helped our working relationship as well as the smooth running of the project. It was especially important as the interviews alongside interpreters took longer to arrange than had been anticipated because we had to negotiate interview times between three parties. Further, this time allowed us to understand some of the content and language specificities, to reflect on the interview process, and allowed me to fill gaps in my understanding. For example, each woman interviewed was asked about her highest educational qualification. The interpreters helped me to understand Indian, Bangladeshi and Pakistani educational systems so that I could classify the type of education gained (see appendix 1).

Regular contact, briefing, the provision of adequate resources and time for debriefing and reflection form a good model for future work of this type. These methodological lessons have implications for service provision when recruiting, training, supporting and working alongside interpreters in health services. In the current study, the process of briefing and reflection might have been improved by bringing the two interpreters together to exchange advice and give mutual support. However, time for more formal meetings and debriefing was limited, firstly due to the demands of the project (many of the interviews took place in the evenings); secondly due to the responsibilities of the interpreters themselves in their daily lives (both were in paid employment and both had school aged children); and thirdly due to my inability to pay the interpreters for any further time. Finally, the timing of the interviews complicated the possibility of bringing the two interpreters together. The interviews alongside interpreters were conducted in two batches. One interpreter assisted with interviewing Indian and Pakistani women and the other helped with interviewing

Bangladeshi women. This meant that there was little overlap which might have allowed me to bring the two interpreters together.

The need to be flexible and patient in the research situation when working alongside interpreters were also important lessons learned. These interviews were inevitably slower than the others and required patience and skill. Working with interpreters was beneficial in that it added to the sensitivity of the research process. It also assisted pathways to potential interviewees as a number of the women were known to the interpreter and this made for a comfortable environment in which to talk. When conducting the interviews, the interpreter and I almost always arrived together. This aimed to avoid making the women interviewed feel uncomfortable given that I have no skills in South Asian languages. After introducing ourselves and assuring confidentiality, we explained briefly our respective roles, and stressed that the interpreter was there to assist the conversations and that I would speak in English. The three way conversations that followed allowed the targeting of follow-up prompts to add further insight. The interpreter then relayed this information back in both first and third person as this made the task of interpreting easier. As the interviews progressed, the interpreters used prompts themselves, without my input, with the aim of expanding on the women's viewpoints and perspectives.

Like the interviews conducted in English, the overall aim was to make the interviews an interactive process. Where it was just not possible to translate verbatim, the interpreter had to make a decision about the information that was relayed. This inevitably affected the trains of thought that were followed up and the prompts that were used subsequently. However, the advantage of such a process was that it increased the interaction in the interviews, making them a more satisfying experience for all parties.

The need to decide which information was relayed raises the question of the accuracy of the accounts. The disadvantages of such an approach were firstly, that some of the detail of the women's experiences and perspectives was inevitably lost. Secondly, given that interpreting from one language to another is very complex, this may have led to subtle differences in the meaning being conveyed. It must be emphasised, however, that 'no single correct translation from one language to another is possible' (Edwards, 1995: 62) and that translation is not an exact science because the context associated with similar words inevitably differs in subtle respects from language to language (Williams, Bhopal *et al.*, 1993). One way of avoiding these problems may be to use back translation where another

interpreter is used to check the meaning of the translated material, but as noted above this option was not open to the study. It is my impression that the women's perspectives and experiences were relayed as accurately as possible and that issues about accuracy must be seen against the need to make the interviews as interactive as possible.

The use of interpreters also presented other disadvantages in terms of the information conveyed. Communication occurs not just through language but through non-verbal means, through gestures and intonation for example. Working alongside interpreters might mean that these aspects of communication are lost to the analysis. This may be because the use of interpreters and the speed of interviews means that what is relayed inevitably focuses on verbal material. I would argue, however, that such losses are not specific to studies on minority ethnic groups which are assisted by interpreters. Such information may also be lost where the language is shared by the interviewer and interviewee, when employing interviewers in studies or when a researcher does not pick up on such information in interviews.

Another disadvantage of working alongside interpreters was that in some instances I did not feel effective in the research situation and felt deskilled and like an onlooker (see section 2.8.2). As the interviews progressed this was shown where the interpreters used prompts themselves without my input. On reflection, however, such a practice also presented a number of advantages. Firstly, it urged the women to elaborate on their healthcare experiences and perspectives. Secondly, it indicated that the interpreters were more than a conduit for information and that they were reacting to the research situation on both verbal and non-verbal levels. This supports other work on the use of interpreters in interviews (Freed, 1988). One lesson learned is that whilst I think that we formed good working relationships, in retrospect I could have been more relaxed towards the interpreters' role in the interviews and facilitated them taking the lead a little more.

Other work highlights some further potential disadvantages of working with interpreters. For example, bilingual speakers rarely have equal abilities in both languages (Pfeffer and Moynihan, 1996; Roberts, 1996), interpreters may be unwilling to divulge information that may put the interviewee's community in an unfavourable light or reveal individual 'bad' experiences (Freed, 1988). Similarly, interpreters may prefer to reveal 'correct' answers to questions, and may fail to translate, mistranslate or edit replies (Pfeffer and Moynihan, 1996). In the current study, it was not possible to check whether this was occurring without

the option of back translation. Once again, however, I would argue that such potential disadvantages are not specific to conducting interviews alongside interpreters or to work on minority ethnic groups. In interviews conducted in one language an interviewee may 'withhold' information for precisely the same reasons.

The only way to tackle these disadvantages is to ensure confidentiality, to be sensitive to the views and experiences of those interviewed, and to build in time to involve interpreters and time for reflection. It must be emphasised that the advantages of working alongside interpreters outweighed the disadvantages (section 2.8.2). The disadvantages must be seen against the alternative of not including non-English speaking women in the study and not providing for those who felt more comfortable being interviewed in South Asian languages. Another way in which the process could have been improved would have been to ask the women interviewed about their experience of working with interpreters and about their ideas for improving the process. However, this was complicated by the extra time that would have been needed to do so (given the resource constraints). Further, it would have been complicated by the fact that the interviewees would have had to talk through interpreters themselves.

Much was gained from the involvement of interpreters in the interview process. This section has highlighted the need to challenge the invisibility of interpreter in studies conducted in languages other than that spoken by the researcher. This supports Edwards' (1995) call for the role of the interpreter to be seen not as something to be 'damped down' but as something to be made visible in the research process. Following this through, one further implication is that interpreters/advocates/community researchers should be involved in research design and analysis as part of a research team (Edwards, 1995) and that these roles also need to be acknowledged. Further, it must be recognised that such practice requires resources, which were unfortunately outside the scope of this study. These methodological lessons have implications for service provision when recruiting, training, supporting and working alongside interpreters in health services as well as for training professionals working alongside interpreters. I have drawn attention to some of the difficulties that interpreters might face, the play-offs that need to be made and the need for time and resources.

In retrospect the dynamics of the interview process appear more complicated. The next section turns to issues of 'race' and gender difference in methodology and interviewing. This adds to an understanding of the dynamics of the interview process.

2.7 'Race' and gender difference in the research process

The previous chapter discussed the tendency to look at either 'race' difference, gender difference or culture in explanations of minority ethnic groups health experiences or women's health experiences. And it challenged a literature that often takes one factor at the expense of others in explanations of minority ethnic groups' health experiences. The tendency to look at either 'race' difference, gender difference or culture is paralleled in the literature on the research process. In this section I draw on debates in feminist methodological approaches and what might be termed anti-racist research approaches to inform my study. However, although much work on minority ethnic groups says that research needs to be anti-racist, there is little written about what constitutes anti-racist research and what it might mean. Debates about anti-racist research remain underdeveloped. As noted in chapter 1, the majority of theory development about racism is not research related in the sense of trying to develop an anti-racist position, rather it has taken place at a theoretical or a policy level. Whilst I acknowledge that there is diversity amongst feminist methodological approaches (Williams A., 1993; Reinharz, 1992; Gelsthorpe, 1992) I will use some key issues in feminist methodological debates to lead the debate and inform my study. I then use these debates to inform my experience of conducting the research. This supports Rhodes' (1994) call for a discussion of similar issues in the representation of views of people from racialised groups and the need for more faithful reflection on the views of such groups.

Central to debates in feminist research and what might be termed anti-racist research is the question of who conducts research and the need for shared experience in research on women and on minority ethnic groups. Section 2.8 expands on the dynamics of the research process and illustrates this with respect to three key themes which arose during the course of my study. These are the researcher's own positionality in the interview process, support for interviewees and the use of interpreters.

Feminist researchers argue for women's views of the world to be properly represented and for methods to support this (Opie, 1992; Roberts, 1992; Ramazanoglu, 1990; Oakley, 1988;

Finch, 1984). More work is required, however, to consider adequately differences between women in the research process. As Ramazanoglu (1989) notes, while women's voices have been increasingly heard in defining research questions, the research process and in the interpretation of results, little attention has been paid to distinctions of 'race' and class within the category women. Feminist research has only gone so far in embracing women from racialised groups in the research. Feminist research with minority ethnic women remains underdeveloped (Bowes and Domokos, 1995a). 'Black women have been perceived as 'hard to reach and hard to research'' (Douglas, 1996: 13). So far this work tends to privilege gender at the expense of 'race' difference; and at the expense of grasping the relationship between gender and 'race' issues in research.

There are similarities in the work addressing 'race' and gender difference that are relevant to my work. For example both urge an examination of inequality and empowerment in the research process. Feminist perspectives start with and emphasise women's experiences (Williams A., 1993; Gelsthorpe, 1993) and the actualities of their everyday worlds (Harding, 1987). Gelsthorpe (1993) argues that feminism is able to inform studies in two ways: firstly, in terms of the research process and secondly, in terms of the choice of subject or research questions which have focused on areas sympathetic to women and made women visible. They would therefore develop analyses that take into account sexism and gender bias. Similarly, anti-racist research approaches might move toward adequate representations of minority ethnic groups' views and concerns. They might develop analyses which take account of, and challenge, racism and challenge prevalent stereotypes. They might also aim not to make racist assumptions, not to interpret data in a racist way and not to reify concepts that are racially defined (Bowes, personal communication).

Feminist debates and anti-racist research approaches alert us to the issue of how knowledge is produced. Some feminist researchers have promoted small scale ethnographies in research on women which allow informants to speak for themselves (Oakley, 1988; Finch, 1984). They suggest that a 'special relationship' is formed between women researchers and the women researched due to shared gender based experiences. Roberts (1992) and Finch (1984) attribute this to the idea that women are more used to accepting questioning about their private lives, and are responsive to informal interviewing which takes the form of an intimate conversation and in which women welcome the chance to talk to a sympathetic listener. This approach, it could be argued, 'empowers' the researched so that a 'more authentic' account of the women in question will emerge. Further, anti-racist approaches

might alert the researcher to avoid methods of data collection which predefine minority ethnic groups' concerns, predefine questions and mould responses into preconceived forms.

Feminist perspectives alert researchers to issues of power and control which are considered to be central in the research process. For Ramazanoglu (1990) these issues are crucial to a successful feminist sociology, where research strives toward ways of knowing, that avoid subordination (Ramazanoglu, 1992). Anti-racist approaches might also address issues of power in the research process and arising from a racist society. For example, they might pose questions about majority ethnic women defining questions for minority ethnic women or about issues of interviewing minority ethnic women by majority ethnic women. Both feminist and anti-racist research suggest that the empowerment of the researched is the way forward (Bowes, 1996).

The notion of empowering the researched has, however, been a cause of some debate. Gelsthorpe (1992) suggests there is a danger of creating 'false-equity' where feminist researchers negate their own strengths and knowledges so they can minimise differences between women. Bowes (1996) questions the nature of empowerment as a universally desirable goal, stresses the need to examine the negotiation of power in research and that empowerment remains an issue for debate. Opie (1992) also takes a critical stance on empowerment. She criticises the way that some researchers impose their feminist ideology on the researched, assuming that they wish to be empowered in particular ways. She highlights the potential for appropriation of interviewees through textual practices after the data is gathered. I agree with Bowes and Domokos (1996) that this potential stretches into analysis and representation of data (see section 2.9). Issues of power also feature in debates about 'race' difference and the research process (discussed below).

Feminist approaches alert us to issues of hierarchy in research. They aim to minimise the hierarchical relationship between informants and researchers. They urge more interactive ways of working and a rejection of 'traditional' methodologies which tend to objectify those being researched (see Oakley, 1988). Similarly, anti-racist research approaches might also alert us to hierarchy, for example it might debate research on minority ethnic groups where a majority ethnic researcher represents power (see later). A number of feminist authors identify the need for reflexivity in different areas of the research process (Williams A., 1993; Opie, 1992; Roberts, 1992; Ramazanoglu, 1990; Hammersley and Atkinson, 1983). Firstly, in the interviewing process reflexivity may be achieved by making interviews an

exchange process rather than a monologue and by responding to the concerns of the interviewee (Opie, 1992). This involves building rapport where the researcher becomes an active listener so minimising the hierarchical relations between the researcher and the researched. Secondly, authors identify the need for reflexivity in accounts of methodology which should stress experiential aspects (Reinharz, 1992). Thirdly, there is a need for personal reflexivity in the research process. Finally, authors have identified the need for reflexivity in analysis and textual practice. They stress the practical and immediate detail of writing up research (Reinharz, 1992) (see section 2.9).

Feminist approaches also recognise diversity. Opie (1992) argues that an important feature of feminist research is the presentation of 'fissured' accounts that recognise different and competing voices. Although this places the spotlight on diversity and difference, these strategies have generally failed to consider adequately issues of 'race' difference and its significance for the negotiation of power in the research process. Anti-racist research approaches might seek to challenge this.

The failure to address issues of 'race' difference in feminist research occurs despite these broad similarities in work addressing 'race' and gender difference in the research process. Debates on feminist research and in research on racialised groups have focused on the power relations flowing from the social positioning of informants and researchers, and have centred on the question of who carries out research.

These debates stress the appropriateness and inappropriateness of similarities and differences in the experiences and characteristics of the interviewee and the interviewer and their effects on the research process. In essence, the argument is that closeness of identity and the matching of the researcher and the researched is said to make for 'better' studies and reduce power inequalities. Shared culture, shared experiences and characteristics may affect access to certain understandings and give more sensitivity to the experiences that research tries to represent. Additionally, power inequalities can be 'controlled for' if researchers and the researched are matched racially in research on racialised groups or if women are matched with women researchers (Finch, 1984) in research that is 'on, by and for women' (Gelsthorpe, 1993: 87).

I will argue that the dynamics of interviewing are more complicated than these debates on 'race' and gender difference would have us believe. There are a number of criticisms of the need for matched interviews. These are examined below.

In terms of shared gender based experiences assisting the research process, Gelsthorpe (1993, 1992) is critical of approaches that insist on shared gender experiences in feminist work and of the implication that women possess a privileged means of knowing over men in research on women. She argues that men can hold a feminist perspective that is sufficiently sympathetic to women's position. Similarly, Kazi (1986) and Ramazanoglu (1989) argue that researchers can adopt anti-racist perspectives without having direct experience of racism. Bhavnani's (1991) study of black and white young people shows that white groups can have 'knowledge' of racism by virtue of shared social networks with black peers.

Racial matching of the researcher and the researched is often seen as an anti-racist research strategy (Rhodes, 1994). This issue has been debated from a number of different positions, for example from the perspectives of black researchers (e.g. Douglas, 1992), white women researchers (Bowes and Domokos, 1996; Rhodes, 1994; Gelsthorpe, 1993) and from the perspective of white male researchers interviewing South Asian women (e.g. Donaghy, 1995). These debates have gone some way toward satisfying Stubbs' (1993) call for the role of white researchers in work on minority ethnic groups to be placed under greater scrutiny.

In common with issues of gender in the research process, power and shared experience is central in the debate about matched racial interviewing. Concern centres on the power relations in research on racialised groups by majority ethnic researchers, their effects on the information gained and on issues of sensitivity to the experiences of those from racialised groups. According to Rhodes (1994: 549), supporters of matched racial interviews argue that a lack of 'insider perspective', shared experience or shared racial identity may mean that white researchers distort the quality of communication and therefore, the quality and 'truth' of information gained. Where a white researcher represents power, which is reinforced by other factors such as class, supporters of matched racial interviewers argue that dimensions of minority ethnic groups' experiences are invisible to white researchers and that researchers might interpret data in a prejudiced way (Rhodes, 1994). Here then, ideas about 'race' difference are regarded as potential contaminants of the research situation.

According to Rhodes (1994) a lack of insider perspective is in danger of confusing cultural misunderstanding with inequalities in power relations flowing from 'race' difference. Douglas (1992) for example argues that racism is fundamental to black women's experiences and that white researchers cannot fully comprehend such experiences as they do not

experience racism. She sees this as an important omission and that research is impossible without shared experience. She continues that white women's accounts and representations of black women's experience fail if they assume that shared gender based experiences outweigh class and 'race' difference.

Further criticism of the need for matched interviews centres on the focus on single factors in explanations of the research process, the notion of ideal positions in research and notions of 'truth' and reality in social research. Each of these criticisms is examined below.

The first set of criticisms of the need for shared experiences as the basis for research is that the argument is too simplistic and essentialist. The stress on matched interviews assumes for example, that all minority ethnic groups experiences are circumscribed by racism and that racism is the only meaningful concern of racialised groups.

Bowes and Domokos (1995a) criticise the essentialism these arguments promote, and disagree with the idea that only women can understand women, and only minority ethnic groups can understand themselves. They argue that other dimensions of experience also come into play in research situations for example age, gender, class, education, lifestage, migration and ethnicity. They then dispute ideas about the effects of a single overriding factor in the research process. In contrast to Douglas (1992), Kazi (1986) urges women to research in partnership provided stereotypes are dropped and racism is challenged and to explore the relations between 'race', gender and class. She urges us to drop the idea that shared experience provides a claim over truth. In addition, shared experiences on account of 'race' difference assume homogeneity in experience and harmony among minority ethnic groups. This disguises the heterogeneity that exists among minority ethnic groups. Similarly, shared experiences on account of gender assumes that women are homogeneous and there is common unity among women.

The second set of criticisms of approaches which insist on shared gender or 'race' experience as the basis for work arise both in recent work on minority ethnic groups (Bowes and Domokos, 1995a; Rhodes, 1994; Gelsthorpe, 1993) and on women (Oakley, 1988). This questions the notion of an ideal position for the researcher. Critics argue that there is always some social ground that remains unshared. The researcher is in a position of power by virtue of his/her profession. For example, the researcher retains control over the production of knowledge, retains the power to define (Bowes, 1996) and the ability to address wider audiences. In addition, the researcher will always bring his/her own world

views and experiences into the research setting and is rarely of the same position as the informant in terms of class, 'race', gender or experience. Also he/she cannot be wholly detached or impartial (Gelsthorpe, 1993) or 'transparent'. According to Donaghy (1995) no one reads from a neutral or final position. Furthermore, as Rhodes' (1994) research on black foster carers shows, the effects of positionality vary with the topics or types of questions and context discussed (see below).

The third set of criticisms of the need for shared experiences in the research process come from studies that dispute the existence of an 'uncontaminated' interview and the notion of a 'true' account of the interviewee. Rhodes (1994) criticises the notion of a single 'truth' or reality contained in accounts from interviewees. She draws on Cornwell's (1984) work that differentiates between 'private' and 'public' accounts and challenges the idea that private accounts are superior or to do with more 'real', 'accurate' or genuine feelings or experiences than public accounts. Both forms have a purpose in social interaction 'but they are nevertheless 'real' or honest to the person expressing them' (Rhodes, 1994: 548). Other studies show that the information gained or attitudes expressed depend on the social situation in which they are formed, in this case the interview (Rhodes, 1994; Mooney, 1994). Truth again is disputed. Studies also challenge the notion that matched interviewees and researchers can gain more 'truthful' or superior accounts. Rhodes (1994) highlights differences in responses of some interviewees to matched interviewers and some negative responses in her study on prospective black foster parents. In the health field, Donaghy (1995) criticises the notion that minority ethnic researchers can produce 'better' research. Ahmad (1993a) and Howlett *et al.* (1992) feel discouraged by and criticise sharply particular minority ethnic researchers' work on minority ethnic groups as damaging and problematic.

The call for matched interviews also carries some wider implications for research on minority ethnic groups. With Rhodes (1994) I would argue that the insistence on matched interviews may risk perpetuating the marginalisation of minority ethnic issues and minority ethnic researchers away from mainstream inquiry so consolidating the position of such researchers at the bottom of the research hierarchy. In effect, this would mean another form of 'intellectual apartheid' in studies so criticised by Ahmad *et al.* (1989a: 54), as discussed in chapter 1. These concerns of marginalisation and representation are those which research on minority ethnic groups and healthcare might otherwise seek to redress.

If 'uncontaminated' or 'true' accounts and an ideal research position are impossible, studies must provide a developed account of the research process. In the light of my criticism this should contain a number of key elements. Firstly, sensitivity to issues of power should be integral to research (Rhodes, 1994). Secondly, the researcher must be open to and reflect critically on factors influencing accounts including the imperfections of approaches. Thirdly, accounts should recognise the effects of difference in social position throughout the research process, from collecting views to the representation of results. I would argue that if studies focusing on racialised groups acknowledge the social position of the researched, then it is foolish to obscure the researchers' own social position and its effects on the research process. Finally, researchers must then write themselves into research and view it as a social interaction in which both the interviewer's and the interviewee's positionality plays a role (Bowes and Domokos, 1995a; Bowes, Dar and Sim, 1995; Mooney, 1994). This moves away from single factor explanations of the research process, away from the idea of an ideal research position and from the idea that there is a 'true' version of the story one is trying to represent.

This section has drawn on debates in feminist, and what might be termed anti-racist, research. It has discussed the issue of the negotiation of power flowing from different social positions occupied by researchers and interviewees. It is clear that the social identities of researchers are relevant to the interview process (Bowes and Domokos, 1996). Writing oneself into the research is part of the data and is a source of knowledge. Below I turn to the dynamics of my own research experience and discuss this issue and its implications in terms of my study.

2.8 The interview process

2.8.1 Reflections on the interviews

My own research experience has shown me that both my gender and my minority ethnic background and a number of other factors affected the progression of my study and the understandings gained. My heritage is half majority ethnic British and half Punjabi, and I was born and brought up in Britain. I share gender with the women I came to interview and to some extent I share a similar social position to the interviewees including the experience of racism in a number of areas. My age, majority ethnic background and social class differs

from a number of the women interviewed. This presents a different position to be drawn on compared to many of the studies cited above.

As noted above, arguments supporting the need for insider perspectives and matched racial interviews presume that different identities inhibit communication in the research process. I will argue that the issue of communication in interviews is not so simple. The accounts show that not only similarities but also differences in positions and life experiences featured in the research process. Both affected the trust and rapport built in the interviews.

My shared gender and ethnic background can be said to have assisted my access to the groups I wished to interview. A handful of women said that they were happy to be interviewed because this would help them to see 'one of their own get on in life'. One of the voluntary group workers told me that she thought I would have relatively few problems gaining access to a number of women because 'I have a black face...' and comparing my position to a white male researcher known to both of us, she anticipated fewer problems in contacting certain ethnic categories of women because of my gender. Rapport, however, was not solely based on 'race' or gender difference. I agree with Bowes, Dar and Sim (1995) that the initial networking and personal introductions described above, could have had more influence on building rapport.

Shared understandings and trust were assisted by aspects of shared minority ethnic identity. It is my impression that this was the most immediate aspect of my positionality to arise in the interviews. My majority ethnic identity was less acknowledged, I presume because of my physical appearance. I felt that I was under scrutiny in some of the interviews where the women tried to 'place' me throughout. This helped to build trust and meant that the women shaped the interviews in some way. My minority ethnic identity and visits to the Indian subcontinent gave some common ground and became a focus for exchange and self-disclosure. Many of the accounts include questions like 'have you been to India?' or 'where is your father from?'. A degree of ethnic identification is seen in the quotations below:

'I'm speaking to you like that because I know you're partly Asian....' [Sikh woman age 31, 0602]

'OK in my case and perhaps in your case we look a bit more westernised in the sense that we dress more western and we speak English...' [Pakistani woman age 33, 0302]

This woman tried to find about my background:

'I have lived in Delhi all my life so we know about those things, but ideas they are same so I talk to my friend quite a lot. And like if I talk, I can't talk about Delhi with you, have you ever been to Delhi?' [Indian woman age 27, 3501]

Differences in my own experience also facilitated and constrained the process. Age became a factor in some interviews with older women. Mooney (1994) provides a useful analogy in her experience of interviewing those older than herself where she found herself like a grandchild listening to a grandparent. In a few cases the 'grandparents' became impatient when I did not understand things. In one interview my ethnic identity and my age combined in the woman's attitude toward me. Her impatience came from my lack of understanding, being younger than the woman, and from my different ethnic background being born and brought up in the UK. I tackled these types of problems by arranging a further visit to give some breathing space or by pausing to explain the aims of the questions.

It is my feeling that the effects of my own positionality on the research process varied throughout the interviews. This supports Rhodes (1994) findings. For example, the effects of my positionality depended on the type of questions asked. In some interviews women asked for my own opinions about racism in Scotland or social support. I noticed, however, that the women despite shared gender and minority ethnic background did not ask about my own experience of cervical cytology, but asked the interpreters whether they had been tested and about their experiences. This may have occurred for a number of reasons, privacy, age or my unmarried status. It is my impression, however, that differences in my positionality contributed to the different questions asked of interpreters and myself.

In terms of facilitating the research process, my lack of language ability and differences in my upbringing served as talking points. In addition, my position as an 'outsider', outwith gossip networks not least because of my mixed majority-minority ethnic background, my language barrier and my short time in Scotland in some ways facilitated the process. Worries about gossip networks and their effects on the responses gained also feature in other studies on South Asian women (Donaghy, 1995). Points of difference may have also added to the accounts gained. Mooney (1994) considers taken-for-granted understandings given by shared backgrounds. On the one hand this may improve the flow of the interviews as some issues do not need explanation. On the other hand there is a danger that meanings may be wrongly assumed. As in other studies on minority ethnic women (e.g. Thorogood, 1988) my different background led me to question areas that were not obvious to me.

I have shown that interviews are a social process where the interviewee and the interviewer interact. I have examined issues of establishing and perpetuating rapport in the interviews in terms of snowballing techniques, initial approaches and contacting the women I wanted to interview (section 2.4), my own positionality (this section) and the practice of questioning (section 2.6). I would argue that an examination of the interview process should involve an analysis of the voice of the researcher. I will now examine two further issues arising during the interview process: that of support for interviewees and the use of interpreters. Both inform an understanding of the dynamics of the interview process and extend issues in research relations beyond the need for matched interviews.

2.8.2 Interview practice

In practice the interviews comprised more than a series of questions and answers. The conversations that took place enhanced the quality of the interview experience for all parties and the quality of the data gained. I used a number of techniques developed from the pilot interviews and previous interviewing experience to build rapport. For example, I explained what the research was about and assured confidentiality. I also tried to put the women at ease. This was often aided by the interpreter who 'broke the ice'. Initially we talked about issues not related directly to the interview schedule. This acted as a lead in to my questions. Many of these discussions added to my findings and understandings of the research process. Finally, I tried to ensure that the women did not feel pressurised to disclose information.

An analysis of my own voice as the researcher shows that support for the interviewees was demonstrated in a number of ways. Firstly, less direct verbal support took the form of supportive comments. These reinforced what the women had said to me, for example, I might comment 'how do you manage, work and the kids..?' 'it must have been difficult before'. Secondly, non-verbal support included making supportive noises, signs of agreement, nods of the head, asking if the women felt confident to continue the interview, covering my head if a woman did when a male household member entered the room.

The third form of support was self-disclosure. Oakley (1988) criticises 'mechanical' interviewing situations where interaction is suppressed and where interviewers whilst eliciting information from interviewees give no information in return. She also disputes the notion that interviews may be biased or contaminated by disclosure on the part of the interviewer. Having invaded the lives of women, asking them to spare time and energy to

talk to me, some form of reciprocation was seen to be a responsibility of the research process (Bowes and Domokos, 1996). Some of the interviews included direct questions about my experiences or opinions. In other instances self-disclosure was part of the 'natural' course of the conversations (see also section 2.6). As noted above, this revolved around similar life experiences or health and ill health experiences, visits to the Indian subcontinent, life in other parts of the UK for example, 'down South'. More often than not this occurred toward the middle and end of the interviews.

Finally, more direct forms of support were responses to requests for advice on health issues, the organisation of health services or educational courses and information about the voluntary groups that I had come in contact with. In all cases I made it clear that these were my understandings or experiences. In some cases the Health Education material that I had brought with me enabled both of us to address some of the women's questions. This contributed to the reflexivity in the interview situation helping me to be more of a participant rather than playing a defined role as an interviewer.

I also felt that the women were very supportive of me. This was shown in the hospitality I received from drinks, to meals and even dinner to take home. Many women were concerned whether they had answered my questions correctly. Some accounts included comments like '...was that all right..?' or 'I hope my answers were OK'. In these situations I emphasised that there was no right or wrong answer and that I simply wanted to understand their own views and experiences.

Whilst I made every attempt not to cause harm to the women in the process of interviewing, a number of ethical dilemmas can arise from establishing rapport. Finch (1984) for example suggests that establishing rapport may leave women open to exploitation and might mean that interviewees answer sensitive questions which they might later regret. It is difficult to say whether the women regretted any of the information they gave me. In retrospect, my approach could have been improved by asking the women more about their feelings concerning the interview process. In practice, I asked sensitive questions only if they were needed to help understanding and I tried to be open, honest, patient and flexible in my approach.

It was agreed with the interpreters and with some of the women that the best time to talk was when there were few others present. We judged that the presence of others, especially men, might distort the women's responses. This is also seen in other studies focusing on women's

views (e.g. Dobash and Dobash, 1992). In other interviews we had to negotiate the television and children's needs to ensure the women's views and experiences were understood properly and taped. In two interviews the television became a distraction, restricting the flow, so I made an arrangement to return later. Where the needs of others encroached on the process, I asked the woman if she felt able to continue and waited until a particular problem was sorted out. In four cases other women were present for some of the time. In the main, this enhanced the interviews, making them more comfortable for the interviewees. The other women informed the responses of the women who looked to others as sources of help, encouragement and verification. The interviewees clearly trusted the other women and felt they could speak in their presence. Having looked in detail at these interviews I believe that they can stand up alongside the others.

Thirteen interviews involved the use of interpreters. As noted above, debates on the use of interpreters centre on the challenge of preparing questions which retain their meaning in translation and which are meaningful for minority ethnic groups (Bhopal, 1992). I would argue that more debates should consider issues of interaction and rapport in interviews which involve interpreters. My experience of interviewing with interpreters adds to an understanding of the dynamics of the research process.

In practice, three-way conversations were set up between me, the interpreter and the interviewee. Early on it became apparent that it was impossible to interpret each sentence as it was spoken. The strategy used meant that the interpreter listened and interpreted for my benefit, making sense of the story, checking it with the interviewee and allowing some follow up. I felt that information would inevitably be lost whatever technique was used. If verbatim translation was used, the flow of the interview would be broken, making the experience faceless whilst creating huge difficulties for the interpreter in terms of when to interrupt. If potted responses were used then some of the detail of the women's accounts would be lost. In practice then, the interpreters took on more than the role of an interpreter, acting as advocates facilitating the interaction and encouraging the women to express their views. The voices of interpreters in the empirical chapters are prefixed with 'INT.:' and my voice is prefixed with 'S.P.:'. The women's voices have no prefix.

As noted above, debates on the use of interpreters have focused on the validity of formulating questions which retain their meaning on translation. I would argue that verbatim translation does little to invert the power relations in interviews. It also decreases

the power of women to shape interviews. I feel that it is more important to ensure reflexivity in interviews using interpreters and to react to what interviewees are saying. I agree with Bowes and Domokos (1996) that the consistency of interpretation given to the questioner's words by the interviewee is more important than the use of questions which have exactly the same wording. The flexibility of the interviewing approaches allowed me to avoid a series of faceless interviews and ensured conversational flow. In the same way as in the interviews without interpreters (section 2.6), I focused on what the women said and hooked into their responses to form further questions.

The use of interpreters modified issues of control and the balance of power in the interviews. It shifted the researcher's control over the boundaries of the research situation. In parts of some of the interviews I felt like an 'onlooker' and felt disempowered and deskilled more than in the other interviews. In other situations, the interviewee and I found ourselves looking to the interpreter. The power shifted again. My inability to speak any South Asian languages may have compromised the rapport in these interviews, the quality of the interview experience for the interviewee and even the quality of the information gained. Bowes and Domokos' (1996) experience of conducting interviews with interpreters shows that interviewees felt more comfortable with the interpreter and that direct communication between the researcher and the interviewee could threaten effective communication. In my experience of working with interpreters giving support to the interviewee assumed more 'immediate' importance. Simple techniques, for example the use of the interviewee's name in questions, maintaining eye contact or demonstrating non-verbal and less direct verbal support helped to demonstrate respect for the interviewee. In retrospect, perhaps more for me as the researcher, this helped to demonstrate the involvement of all parties in the interview process.

The benefits of using interpreters outweighed any limitations. Constraints on the interaction between all parties varied throughout the 13 interviews. For example, in some instances the women became impatient with the interview process if some of the prompts that followed the main questions translated in a similar way to the main question itself or when I needed time to clarify points. In other instances the women had understood some or all of what had been said in English so that translation was not necessary. This reassurance meant that the woman felt confident to continue her story as she had made her point understood.

In all interviews with interpreters rapport and flow of the conversations was not only assisted by shared 'race' and gender, it was also assisted by trust and respect. All the women knew the interpreter as a friend or in a professional capacity. This shifted the balance of power in the interviews toward the interviewee.

The use of interpreters assisted communication in the interviews beyond language. The 13 interviews were conducted in a number of South Asian languages and dialects, Bengali, Sylheti, Punjabi, Pakistani Punjabi, Urdu and Gujarati. The language used by the women was not a straightforward issue. Some of the women switched their accounts between their particular South Asian language and English. The flexibility of the interviewing technique assisted in this negotiation and, given that these interviews involved one person who could not speak any South Asian languages, it allowed the most effective type of communication to be used (Bowes and Domokos, 1996). My impression was that switching between different languages occurred especially where the women wanted to emphasise points or when they felt able to answer in English. In a number of cases the presence of a known interpreter added to the supportive environment in which the woman was interviewed. This enabled women to speak to me directly and assisted the flow of the interviews. For example, one woman asked for an interpreter to be present because I was not known to her. She then decided to do most of the interview in English.

I have argued that the dynamics of interviews with interpreters are more complicated than first thought and stretch beyond a focus on the use of the same translated questions in interviews. Interpreters/advocates provided invaluable assistance before, during and after the interviews. Extensive discussion with and advice from the interpreters before the interviews gave additional input into the research design (section 2.4) and meant that the interpreters did not go in 'blind' and knew the aims and questions of the study. In addition, they provided invaluable assistance in gauging the interview situation and enhancing my sensitivity to the interviewees. As noted above, all the interpreters were known and to a certain extent knew about the women's own routines. They also helped with language.

Overall the interview process with interpreters was more tiring than some of the other interviews and required more organisation. The success of the interviews stems from the patience and support of the interviewees and the interpreters without whom the conversations would not have taken place. For these reasons I decided to leave most of the interviews that required interpreters until the end of the fieldwork period.

Having organised and carried out the interviews the next challenge was to formalise my approach to analysing them. The next section outlines how this was done.

2.9 Representing and analysing data

Qualitative data analysis is the process of examining the constituent components of data, its elements and structure (Dey, 1993). It is not a separate phase of the research process (Bryman and Burgess, 1994), rather, data collection and analysis inform and drive each other (Tesch, 1990). The literature on data analysis shows that while those involved in qualitative research have become more explicit and reflective about their methods of data collection, little work has addressed and reflected on methods of analysis (Bryman and Burgess, 1994; Richards and Richards, 1991; Lee and Fielding, 1991). As noted above, an examination of research questions and approaches to data collection are vital if one is to examine and represent women's own healthcare experiences and perspectives. In this section I will outline the salient features of the analysis and highlight the advantages and disadvantages of the various approaches taken.

Data analysis aims to describe and classify phenomena, to examine the interconnections between concepts and to make the events being studied understandable. Whilst undertaking the interviews, the volume of the accounts, their complexity as well as the variation in women's experiences and perspectives became apparent. This meant that my approach to data analysis needed to be rigorous.

Data management

The first stage focused on the management of the data. This meant setting up a framework to manage over 980 pages of typed raw data and to examine all the healthcare events, experiences and perspectives of the women interviewed. Data analysis necessitated a systematic approach including familiarisation, categorisation, abstraction and the interpretation of the interview material. In the analysis a computer was used as a tool and a programme called 'Hypersoft' was chosen to assist. All stages are outlined below.

Familiarisation

I became familiar with the material by transcribing the interviews fully. This gave a closeness to women's accounts that assisted the analysis process. As sole researcher and

interviewer I already had an understanding of the data. Through rereading my fieldnotes and reading most of the interviews closely I began to see initial patterns, form ideas and ascertain emergent themes. This process of immersion in the data allowed me to develop an initial set of categories to help analyse the accounts.

Categorisation

Hypersoft, like most computer assisted qualitative data analysis packages, requires the researcher to classify the text into categories which are meaningful for the analysis. Each category represents a theme in the data. A section of text can belong, in whole or in part, to one or more categories and a category can be flagged by a single word or a cluster of sentences. The point is that while the categories are used to group and retrieve the data, they do so in such a way in which preserves the verbal detail of each piece of conversation. To achieve this the data had to be divided into 'bits' of meaning (Dey, 1993) and categories assigned to all the bits that made up each interview.

There are a number of ways to define categories. I chose to adopt a 'middle order' approach (Dey, 1993). This practice enabled me to gain a holistic grasp of themes some way between line by line categorisation (Strauss, 1987) and a broad categorisation of the data (Jones, 1985). The process of defining categories took a number of stages (see appendix 3 for full category list).

The first stage used my research aims and interview schedule to define initial categories. These categories were very simple and were grouped under four main headings associated with access to healthcare in accordance with the aims of the study- access to healthcare outside services, access to the GP, access to cervical cytology and social constraints. Included in the category list were conceptual categories which allowed me to examine women's pathways into and around services, how healthcare was used, and women's attitudes to healthcare and experiences of it. Each section included a 'catch-all' category which ensured that no data were lost and that everything the women said was examined. Some of the category names referring to each healthcare arena were similar. For example in examining the effects of 'race' difference on access to healthcare I used the categories 'Race GP' and 'Race Smear'. This allowed the flexibility to compare different healthcare arenas. I also included purely descriptive codes, for example, women's personal biographies, type of GP surgery, or number of cervical smears. The simplicity of the categories enabled me to remain open to ideas and emergent concepts during the analysis process. According to

Richards and Richards (1994: 149) ‘...methods of handling qualitative data must contain ways of catching and developing ideas, exploring hunches and drawing connections between them and the data from which they are derived’. The second stage of defining categories included categories to arise from the women’s accounts themselves. This helped to refine previously defined categories. The third stage involved the construction of flow charts or ‘code maps’ (Miles and Huberman, 1984) which linked categories together and allowed me to see how they were related.

The final stage of defining categories took place in parallel with the assignment of categories to bits of interview data. The process of assigning a category to a data bit initially involves determining if a particular category or categories fit a particular section of the data. To do this, I read and reread a number of interviews closely line by line, tried to determine the key themes and processes occurring and to reconstruct events (McCracken, 1988). This was assisted by listening to the interview tapes and rereading fieldnotes and notes taken when transcribing. To formulate the categories I selected six interviews which differed in terms of content and length. These included a range of women in all four South Asian ethnic categories across the age range. These were then coded by hand on paper next to the original transcript. This helped to refine the category list. I then carried out some analysis on this cross section of the data.

Categorising a cross section of the interviews gave a number of advantages. Vertical analysis (Davies, 1991), which focuses on one interview at a time, enabled me to familiarise myself with some of the data as well as the principles of coding and splitting up data. It also let me familiarise myself with the workings of the software package and to plan further analysis.

The next stage was to code all the interviews and to sort them systematically, both according to schedule topics and topics the women themselves had raised. The emphasis then shifted from vertical to horizontal analysis (Davies, 1991). This placed more emphasis on the whole data set and allowed further familiarisation with the data and the patterns emerging.

Categorisation allowed the range of comments to be seen easily and helped me to explore the regularities and singularities in the data i.e. majority and minority views. It allowed me to reflect on the data that would otherwise have been lost if the analysis had been less rigorous. A full log of the codes used was kept specifying what each should include. This ensured that the evolution of the codes was documented and that coding was consistent.

Hypersoft

As noted above, my analysis strategy was assisted by a qualitative data analysis package 'Hypersoft'. The choice of the package involved a consideration of appropriateness and cost. Financial restrictions reduced the range of packages available to the study. Hypersoft was chosen as it provided a good tool to use: to retrieve and code sections of data, to enable me to explore connections between data, to retrieve data easily and to cross reference categories. It also allowed me to code sections of data quickly aided by a mouse instead of coding line by line. Computer Assisted Qualitative Data Analysis (CAQDA) made analysis a fluid process. It allowed me to recode bits of data as my categories changed or new ones were added. This avoided the temptation to disregard new data that necessitated recoding.

Data retrieval

The next stage was to retrieve and to analyse the data that I had assigned to my categories. This stage was assisted by cross-referencing with a number of variables, such as age range, generation, and family size that had also been assigned to the data. So for instance I was able to select all comments made by any woman about problems in communicating with her GP, and I could group these comments according to age, family circumstances or ethnic background. This flexibility helped the analysis which became increasingly complex.

Final analysis

The final stage was to analyse the sorted lists of data that were assigned to my categories. Copies of the sorted transcripts were made and interpreted using grids and diagrams to elicit the themes in the data. During the process constant reference was made to the original transcripts. This aimed to minimise any context that was lost during the process of splitting up the data. It also allowed some clarification of the sorted interview material. Analysis was written from these grids and summaries made alongside sorted and original transcripts. The analysis was considered against a backdrop of the existing literature and my own views.

A further challenge or stage in the data analysis is the representation of information gained. This is complicated by the need to articulate information to an audience/readership. My empirical chapters use quotations to illustrate the understandings gained from reading and analysing the data. The selection of quotations reflects a play off between quotations which are shorter and so easier to understanding and longer quotations which represent the

complexity of the experiences of the interviewees. In addition, in selecting the quotations a number of ethical issues arise about how much information to reveal and whether what is presented represents the women's experiences and perceptions accurately. I have used punctuation to assist this process.

Each quotation selected either represents a range of themes or has been selected to represent variability in women's views or experiences. I have tried to ensure throughout that quotations are used from all four ethnic categories. This was possible as each interview was coded according to South Asian ethnic category, and in the event there was more variation within the South Asian ethnic categories than between South Asian ethnic categories and the different categories of women were exposed to many common experiences.

Advantages and disadvantages of CAQDA

CAQDA gave a number of other advantages. Firstly, it freed up time and energy for analysis by reducing the amount of time taken to manage the data (although the time needed to develop and apply the coding in the first place was considerable). CAQDA also helped to remove a number of mechanical tasks, for example storage, recording and retrieval. This allowed fast manipulation and organisation of data (Richards and Richards, 1991). It ensured that the sorting of data did not get in the way of analysis (Richards and Richards, 1994, Lee and Fielding, 1991), freeing up time for initial theorising, familiarisation and reflection. Time saving allowed me to avoid postponing and becoming distanced from the analysis. Assigning categories and making connections was quick and simple. CAQDA increased the speed of data handling and removed constraints on the size of the records without losing the complexity of the data. Secondly, it helped to give me as an 'outsider', and equally crucial to the reader a shape to the data. The flexibility of CAQDA allowed me to manipulate the transcripts into forms that could be analysed systematically.

Thirdly, CAQDA enabled me to be systematic, more rigorous and less 'impressionistic' and to maximise the findings. It allowed me to view the range of findings and to avoid *ad hoc* approaches to analysis. I avoided the tendency to remember only the responses which confirmed my preconceptions (Opie, 1992) and those responses which at first sight might be considered 'more interesting' or colourful. I was able to look at all the responses of women and to assess the range of views and experiences. Fourthly, CAQDA enabled me to consider majority and minority views. It allowed me access to the full range of comments and to make a considered representation of findings. It made it easy to see unusual cases and to

find small but significant pieces of information within the main body of material. Access to the full range of comments assisted the process of verifying my claims. With all the data in hand I could document the number of women holding particular views or having particular experiences. These figures are included throughout the empirical findings and aim to enhance the reader's appreciation of the significance of perspectives or healthcare actions and allow him/her to compare the significance of supporting and non-supporting findings.

Finally, CAQDA allowed me to follow-up sensitive topics that were difficult to talk about or where women had been hesitant. Some of the women understandably found particular healthcare episodes and experiences hard to voice. Whilst I did not push them to talk about sensitive issues, often in my experience, responses to questions flowed later on or unprompted in interviews. CAQDA helped me to include all these kinds of responses, to reassess the material and to consider not only what was said but also how it was said. The understandings then are based on the full range of opinions gained. Nothing was lost, everything was included even if it was not in response to the question being posed at the time.

This section has shown a number of theoretical and practical advantages with the use of CAQDA. Computer analysis also has a number of disadvantages. Firstly there is a danger that the computer package might guide the research design instead of being used as a tool to assist analysis (Agar, 1991) and that researchers might design projects to fit computer programmes (Richards and Richard, 1991; Agar, 1991). In my experience, however, the bulk of the creative process of analysis took place away from the computer. I limited my use of the package to assist with managing, segmenting and retrieving data so that I did not lose sight of the context of women's perspectives and experiences.

Secondly, there is a danger that projects may be driven by what the computer can manage. This may shift attention away from their aims. For example, CAQDA allows larger data sets to be handled and more codes to be used that segment the data. The ability to handle large volumes of data and to quantify occurrences and themes blurs the dichotomy between qualitative and quantitative approaches (Richards and Richards, 1991). It may mean that more attention is paid to volume rather than the depth and scope of findings. I minimised this problem by designing the study with reference to perceived constraints on the time and resources available to the study. In my experience, the potential problems of CAQDA may

be avoided if they are acknowledged and the computer is used as a tool which can offer significant benefits in data analysis.

2.10 Conclusion

This chapter has explored issues of research design, implementation and analysis. It has examined a number of issues including: the strengths of the qualitative approaches adopted and their potentiality for my study, issues of sampling, the process of gaining access to interviewees, the interview process and data analysis. I have reflected on elements of the research process that often remain unacknowledged or disguised, for example, the dynamics of the interview process, establishing research relationships, computer assisted qualitative data analysis and the representation of data. I have debated the strengths and weaknesses of the approaches taken and have argued that an acknowledgement of the limitations of such approaches is integral to an account of methodology.

This chapter has shown that the study did not occur in linear stages but was shaped by the data and its setting. The research design involved a negotiation between the perfect and the possible (Bowes and Domokos, 1996). To gather information appropriate to my research problem I had to negotiate resources, practicalities and make personal and methodological choices, whilst being sensitive to the concerns and judgements of the women involved. This has been shown in my account of sampling strategies and evaluation of my interviewing experience.

A number of central features of the research process contributed to the success of the project. Qualitative research techniques assisted the research process in a number of ways. They allowed me to adopt a subject oriented approach and enhanced the depth of understanding gained. Such techniques enabled an understanding of access to healthcare based in women's accounts and helped to build a detailed picture of women's pathways into, and of their experiences and perceptions of, healthcare. In addition, qualitative research techniques gave flexibility to the research process. This was important in assisting initial access to women through the voluntary sector, and during the process of contacting interviewees, whilst interviewing and when conducting interviews with the help of interpreters/advocates. My study advocates the use of qualitative research techniques in research on minority ethnic women as a more sensitive means of gathering and analysing data than the quantitative approaches that dominate the literature. It adds to a growing

number of studies on minority ethnic groups and healthcare that have used qualitative approaches.

The research process was also assisted by individuals, groups and organisations. These parties were critical in gaining access to, and developing rapport with, the women interviewed. The interview process was also assisted by working relationships with a number of interpreters who acted more as advocates. They helped me not only to translate the words of women but to gain access to interviewees and to define and refine interview questions. They also facilitated communication with women in a number of ways beyond language assistance. These features of the research process contributed to the sensitivity of the methodological approaches taken.

Other central features of the research process included the selection of research tools which were suited to creating the conditions needed to explore South Asian women's perceptions and experiences of healthcare. This included the use of semi-structured interviews and the use of computer assisted qualitative data analysis (CAQDA). Semi-structured interviews were compatible with my research aims and allowed me to include specific questions about women's access to three different healthcare arenas and to create a dialogue allowing women to describe their perceptions and experiences of healthcare. In addition, CAQDA enabled me to manage, sort and work up the interview data. It ensured that the analysis was systematic and that understandings were subsequently based on the full range and depth of the data gained so contributing to the advocacy process. The use of such research tools was in line with my aim to gain a detailed understanding of access to healthcare which is sensitive to the experiences and perspectives of South Asian women.

This chapter has presented a detailed account of the interview process and has drawn on debates about gender and 'race' and methodology which revolve around the question of who carries out research and the need for shared experience between interviewers and interviewees. My criticism revolved around a feminist literature that has not generally dealt with issues of 'race' difference. It concluded that studies must be designed to consider the relationship between 'race' and gender difference in the research process. I have disputed the need for matched interviews in research on women and on minority ethnic groups on four counts. Firstly, debates in the literature on interviewing women and minority ethnic groups challenge the notion of an ideal position of the researcher. Secondly, the notion of an uncontaminated interview or a 'true' account has been disputed. Thirdly, the

essentialism that single factor explanations of the interviewing process promote has been challenged.

Finally, my own interviewing experience also challenges methodological debates that centre on the need for shared experience in research on women and in research on minority ethnic groups. The dynamics of the interviewing process are not as simple as these debates would have us believe. Ideas about 'race' and gender difference affected the research process along with a range of other factors, including age and generation and the changing effects of my positionality throughout the interviewing process. In addition, issues of similarity as well as difference are relevant in a discussion of research focusing on South Asian women. Both affected communication in the interviews, conversational flow and issues of self-disclosure. These findings urge a broader understanding of the effects of positionality in interviewing beyond the need for matched interviews. They are important as I have argued in chapter 1, research on minority ethnic groups and health has tended to be at a policy or theoretical level, not at an empirical level.

Having implemented a successful methodology the interviews revealed a range of views and experiences from which a number of themes were drawn. The next three chapters consider the empirical findings in detail.

Access to healthcare outside health services and South Asian women

3.1 Introduction

This chapter examines access to healthcare outside the formal service sector. This is the first of the three healthcare arenas that will be examined. There are few studies on minority ethnic groups' own views of their health and healthcare (Howlett, Ahmad and Murray, 1992; Ahmad, Kernohan and Baker, 1989a). To fill this gap the women I interviewed were asked about their attitudes to their own health and about their healthcare actions. This chapter examines how the women perceive their own health and explores the way women's health needs are met in the informal sector and how women manage their healthcare in health and in ill health. It also outlines the factors that mediate these health attitudes and actions and reveals a number of constraints and enablements on South Asian women's access to healthcare. My findings challenge a literature on minority ethnic groups and healthcare which has emphasised conventional understandings of cultural difference in explanations of South Asian women's health experience.

3.2 Background: The health and healthcare of South Asian women

There is little information about minority ethnic groups' general health status (Douglas, 1996) or quality of health. In addition, Bhopal and White (1993) note that understandings of minority ethnic groups' health beliefs and behaviours are limited. To date few studies have examined how minority ethnic groups manage health and ill health in their everyday lives.

A focus on this healthcare arena adds to the argument presented in chapter 1 in a number of ways. Chapter 1 showed that understandings of access have centred on service use and noted that most healthcare takes place outside services. This chapter challenges the invisibility of the informal healthcare arena in understandings of access to healthcare. A focus on this healthcare arena also adds to debates in the literature on women's health by

challenging the invisibility of minority ethnic women and their healthcare experiences and perspectives. Additionally, it challenges the devaluation of women's healthcare experiences, where medicine has questioned the validity of other forms of healthcare besides formal health service provision (Roberts, 1985). Throughout this chapter I emphasise that women can provide valuable information about their health experience and healthcare needs.

A focus on this healthcare arena also adds to a number of debates in the literature on minority ethnic groups and health. Firstly, it challenges a concentration on minority ethnic groups' 'different' health behaviours and attitudes. Chapter 1 showed that culturally deterministic research has focused on the differences rather than the similarities between the healthcare experiences of minority ethnic and majority ethnic groups. Secondly, it moves away from 'disease centred' research on minority ethnic groups which measures the incidence of particular conditions and so called ethnic effects on health (Smaje, 1995), toward a focus on the actual healthcare activities of South Asian women themselves and the means of managing health and ill health. It aims to place women themselves rather than disease at the centre of the debate. Finally, a focus on this healthcare arena challenges a focus on specific diseases. Chapter 1 showed that culturally deterministic research has concentrated on a number of specific mental and physical conditions (Bhopal, 1986b; Donovan, 1984), instead I focus on South Asian women's broader views and experiences of a spectrum of issues relating to health, ill health and healthcare.

Recent work on the health status of minority ethnic groups provides useful background to my findings. The following discussion shows that the patterns and relative rates of particular health problems remain unclear, despite a general perception that the healthcare needs of South Asians are greater and their health is poorer than that of the general population (Williams *et al.*, 1993).

Larger health surveys which might help to clarify the picture of health status, such as the Health and Lifestyle Survey, include few minority ethnic respondents. However, some progress in understanding has been made since the 1991 Census which included 'the ethnic question' along with questions on the prevalence of 'limiting long term illness'. The 1991 Census results show that while long term illness affects a slightly higher percentage of South Asian compared to white households, there is less long term limiting illness in South Asian than white households. They also show that rates of ill health among South Asians

are higher than would be expected on the basis of their age structures, especially for South Asian women (Owen, 1994).

The work of Williams *et al.* (1993) and others shows that the picture of minority ethnic health status is complex. For example, there is some empirical evidence to show that patterns of health among minority ethnic groups are not static. Williams R. (1993) found that longer length of residence in the UK was associated with poorer health. As noted in chapter 1, factors other than ethnicity may contribute to patterns of health. Ecob and Williams (1991) emphasise that it is unclear whether health status can be attributed to ethnicity, housing conditions or socio-economic category for example. Recent work on health status and minority ethnic groups by Fenton *et al.* (1995) argues for the use of socio-economic measures alongside ethnicity in measurements of minority ethnic health status. They argue that poorer self assessed health among minority ethnic groups can partly be accounted for by socio-economic disadvantage.

The picture of minority ethnic groups' health status is further complicated by studies which highlight gender differences in health status and differences in health experiences between minority ethnic groups. Fenton *et al.*'s (1995) findings show that poorer health status was more marked for minority ethnic women than men, but was not statistically significant. Like studies on white women (Popay, 1992), Fenton *et al.* (1995) show that minority ethnic women tend to report poorer self assessed health than men. More local work in Glasgow by Williams *et al.* (1993) also shows that the health gap between South Asian men and women between the ages of 30 and 40 is greater than between South Asians and the general population. Other differences in health experience between minority ethnic groups are also becoming apparent. In line with the 1991 Census findings, Fenton *et al.* (1995) found differences in health status among South Asian ethnic categories. Their findings indicate poorer health status among Pakistanis than Bangladeshis, and that Bangladeshis had poorer self assessed health than the Indian group.

My study cannot comment on relative rates of health and ill health between South Asian women and other groups or among women in different South Asian ethnic categories, and it does not aim to ascertain women's knowledge of predefined health issues as other work has done (e.g. HEA, 1994; Bhopal, 1986b). Rather, my aim is to focus on women's own discussions of their health and healthcare and their health experience. I examine how women themselves define and talk about their health, how they manage health and illness in

their everyday lives and the factors that affect their healthcare experiences. The result is a fuller picture of the factors affecting access to healthcare in this arena and some insight into how access can be improved for South Asian women.

3.3 Health Attitudes

Ideas about health and ill health are an important part of the decision to implement or seek out sources of healthcare, including health services. Therefore, in order to examine access to healthcare for South Asian women it is necessary to examine women's own attitudes to their health and healthcare. This will help us to understand how South Asian women experience health and why they use healthcare in particular ways. This section describes women's self assessments of health and includes their worries about health and reasons why they want to be healthy.

3.3.1 Women's perceptions of health - assessments of health

The women talk openly and sometimes at length about their health. In this section I will show that women's accounts of health and ill health cannot be separated from what is happening in the rest of their lives. Their descriptions of health highlight intersections between health and life courses. For example, many women make sense of their own health by linking it to: the health of others, especially their families; to past states of health; to particular places; or to life changes such as migration. Intersections between health and life experiences run throughout the empirical findings.

As noted above, women's experiences of health and ill health, together with their attitudes toward health and healthcare are important factors in mediating access to healthcare. While my study is not designed to make quantitative assessments of the prevalence of morbidity among the interviewees 22 women say that they worry about their health.

Eight women are worried about specific or ongoing health problems. Three women have asthma, two have diabetes and six have anaemia. Six women are also worried about other undiagnosed problems. For example, three women complain of backache, others identify stress and worries (see below) and some identify period problems [6 women] or migraines [5 women]. Some attribute their health problems to environmental factors such as isolation

[4 women], housing [2 women] or the weather [9 women] and describe how these problems affect them in their daily lives.

Some women are concerned about changes in their health state. These worries are specific. For example, a frequently mentioned concern is weight, both to lose it or to gain it [10 women]; another concern is the menopause [4 women]. Other health concerns relate to health changes over time. For example, changes in health with age [2 women] and changes due to hereditary health problems [3 women]. Other women are concerned about the development of particular long term health problems [4 women].

It is not possible to make statements about relative morbidity among the South Asian women interviewed compared to others. Other work, however, outlines high levels of asthma and diabetes among South Asians in Glasgow (Williams, Bhopal and Hunt, 1993). Concerns about weight are also supported by epidemiological studies for example, the Twenty-07 study in the West of Scotland found that South Asian women are more likely to be overweight than women in the general population (Williams, Bhopal and Hunt, 1993).

The interviews also reveal significant levels of perceived psychological ill-being. It is difficult for my study to comment on relative levels of psychological ill health among South Asian women and the general population, given the nature of the study, and because the evidence for rates of psychological ill health among minority ethnic groups is contradictory (see section 4.4.2).

Some women describe a strong sense of lack of well-being as well as stresses and worries in their lives. Sixteen women say that they have worries or are depressed, another two women identify periods of stress and worries. Four of the 18 women volunteer that they have received treatment for psychological ill-being. These levels are broadly in common with the studies of Williams *et al.* (1993) and Bowes and Domokos (1993) in Glasgow, but differ from Currer's (1991) data which show lower levels among Pathan women in Bradford. The majority of the worries reflect those of other women. In common with other work on white women (Popay, 1992), their worries are linked to their families, the household, pregnancy, isolation/loneliness and to pressures on the use of space outside the household. Other worries relate to work, persistent health problems, bereavement and to families and friends abroad especially those in the Indian subcontinent. All these areas broadly reflect those found in other studies on GP practice populations in Lothian (Hopton and Dlugolecka, 1995). Many of these determinants of health and quality of life are out of the control of the

individual. They cause or exacerbate feelings of ill health and are perceived to affect both physical and mental health.

Further concerns relating to health and well-being, are specific to those who have migrated from country to country and to racialised groups in society. During the course of interviewing many unprompted discussions tried to make sense of racism and its effects on health and well-being in daily lives. This is discussed in detail in section 3.6.2.

The detail of the interviews shows that definitions of health and ill health consist of much more than a simple awareness of symptoms. Crucially, health and ill health is something the women negotiate in the context of wider demands and expectations in everyday life.

It is important for the women to describe themselves as healthy. When discussing their own health, 29 women describe themselves as generally healthy, three as unhealthy. Nine women feel that their health is worse relative to women of a similar age and six women feel that it is better. The women feel that they need to be healthy in order to fulfil certain roles and expectations. Interviews with 10 women include the functional dimensions of health. This refers to an individual's subjective awareness of limitations in functioning i.e. how health hinders everyday activities (Susser, 1973). Eleven women's descriptions of health include the social dimensions of health. That is the socially accepted limitations that health places on an individual's role in society (Susser, 1973). This woman shows how a sense of well-being is threatened when health is threatened:

'Health is the most important thing I think so. If we healthy we do everything if we don't have healthy we can't do everything, even eat properly, even to find out some work or like that things so that happens [happened] last year and we survived very hardly that's it' [Pakistani woman age 27, 3101]

'No I healthy that's all idea nothing to do. I feel all right you know, I am not any illness things you know, that's why...I can work you know. If I is ill or anything I can't work [laughs].' [Indian woman age 59, 1504]

'If my health is good I can cook myself, I can do whatever I like. If my health is not good I depend on other people...If my health is good I can cook...This is best for you...' [Indian woman age 51, 0404]

The interview data indicate that in order to get on with life it is important for the women to define themselves as healthy. The women tend to do this even when they experience health problems or problematic symptoms:

'My health I'm fine. A bit asthmatic because I am allergic to dust, otherwise I am fine.'
[Sikh woman age 42, 0903]

In effect, describing oneself as healthy may mean overlooking episodes of ill health. This woman only feels ill if her back problem reoccurs, otherwise she describes herself as healthy despite colds or flu:

'I only get ill when my back goes otherwise if I caught a cold or flu I just carry on doing everything...' [Indian woman age 27, 3501]

Such descriptions of health tell us something about the way women think about particular symptoms. In particular, they show a reluctance to define certain health problems as ill health.

The negotiation of health affects women's propensity to seek healthcare. These aspects of the interview data suggest that it is material factors rather than ideas about South Asian culture which condition the need to be healthy.

The interview data also show that definitions of health are negotiated in relation to places and times. This means that the expression of health needs varies from place to place and time to time. To negotiate health the women use a number of reference points linked to place and lifestage which allow them to make sense of their health. This woman is typical of five women who describe their current health and compare it unfavourably to their health before they had children:

'My health? Not very bad but I've got problems. I was quite healthy when I was young, very healthy. I rarely had cold and all these flu and anything like that... used to eat healthy food and you know [after I] had children I was all right but started putting on weight...' [Pakistani woman age 54, 2104]

Current perceptions of health are linked to accounts of health in particular places. Five women stress that they have been healthy since they have been in the UK and refer to their past states of health in the Indian subcontinent. These accounts show how women use shared cultural references in their discussions of health and reflect on their cultural heritage to bound their stories. Place is used by a range of women, not just older first generation women who have generally lived outside the subcontinent for longer periods and spent a greater proportion of their lives in the subcontinent compared to younger first generation women. This woman has been living in the UK for over 20 years:

‘S.P.: How would you describe your health?

What do you think about it? I am all right since I came here [to the UK] no. I am never ill till last year. Last year I got some problem arthritis you know. Then some of like that you know, arthritis and some blood bladder things like that...’ [Indian woman age 59, 1504]

This section has shown that the women negotiate health in a variety of ways by describing themselves as healthy, ignoring ill health and by describing their health in relation to different places and times in their lives. It has also shown that women are worried about their health and how their health affects them in their daily lives. This has implications for their help seeking behaviour and their use of health services. These aspects of the data suggest that women’s use of sources of healthcare is not as great as it otherwise might be. The next section examines the management of ill health and health maintenance in detail. The accounts support my argument that healthcare is more than just the use of health services.

3.4 Healthcare Actions

Having examined women’s attitudes to health I will now focus on women’s healthcare experience which is integral to my conceptualisation of access to healthcare. Sections 3.4.1-3.4.2 examine how women’s health needs are met by the informal sector and focus on how women maintain their health and cope with ill health. The accounts reveal a great awareness of women’s own health and healthcare practices including preventative and curative health behaviours. The following analysis is based on women’s accounts of healthcare in its everyday context.

3.4.1 Maintaining health

The women were asked how they keep themselves healthy. It is clear from the accounts that women feel they can change their health for the better and that they are keen to enhance their knowledge about health and healthcare. The accounts identify both curative and preventative health behaviours. They show that ways of maintaining health are both active and passive.

As noted in section 1.7.1, current health policy emphasises the use of primary care services to help to keep oneself healthy, marking a shift in the nature of healthcare provision from cure to prevention. In the main, the interview data show that the responsibility for

maintaining health lies more with the individual and less with health services. It is notable that when questioned about health maintenance, only five of the women voice ideas about the use of health services, specifically primary care services, to keep healthy. Four of these women talk about health checks in clinics for older women; three others talk about cervical cytology as a means of keeping healthy; and three of the women talk about dietary advice gained from their GPs or diet clinics at the surgery; one other woman mentions trips to the dentist. More ideas about the use of primary care services such as health visitors, family planning clinics, casualty departments and physiotherapy arose later in the interviews and were linked to women's actions in ill health rather than their actions to keep healthy. These findings support my argument that understandings of access to healthcare should include healthcare beyond service use.

One of the central conclusions from the interviews is that maintaining health is linked to women's daily routines and daily lives. The women's ideas about their means of maintaining health are linked to the health of others, especially their families. Their accounts of health maintenance are punctuated with ideas about their family's state of health, as well as their own. This leads 11 women to feel that they 'do not really do anything to keep themselves healthy' or 'do not think consciously about keeping healthy.' Some of the women's responses to questions about health maintenance start off with statements like 'Nothing, I don't do any exercises or nothing, just the way I am...' The everydayness of health maintenance is illustrated by the women quoted below:

'I don't think I've really thought about it. I just get up and do the everyday things that I do. Just get up and feed the kids, clean the house, go to work, come back. I don't think I really sort of think about health...I think to me there's more important things to do apart from thinking about my health. The day to day things...' [Indian woman age 33, 2002]

The everydayness of health maintenance is linked to a perception that methods of health maintenance are part of common sense:

'S.P.: Where do you get these ideas about health?

They are actually I take myself. This is actually common sense, good food is good health.' [Indian woman age 51, 0404]

Some health behaviours identified by the women may be considered to be more 'passive' than others. They talk about keeping healthy as part of an everyday routine. For example, five women identify everyday religious practices as a factor affecting their good health and well-being. Seven women specify working hard or keeping busy as a means to keep healthy.

In addition, five women say that work around the home keeps them fit. Others talk about avoiding certain behaviours as ways to keep healthy. Most of this relates to diet (see below) although some women emphasise the dangers of particular behaviours such as smoking [1 woman] and drinking alcohol [1 woman] which they avoid. These women are typical of those who talk about keeping healthy in the course of a normal day:

‘S.P.: How do you keep healthy?

I don't know, maybe probably working hard, I think so. A routine, you get up and do prayers and clean house and now my daughter-in-law is here, she helps me a lot... I am already a lot of things on me. And to shop regular[ly] [family business] for five hours, come home do prayers at night, and then watch what's on telly or go out somewhere. Try to walk a lot after my dinner sometimes...’ [Sikh woman age 42, 0903]

‘S.P.: How do you keep yourself well?

I don't really do, I think I am busy, it's a lot of exercise. I don't really go to exercise classes...I feel with my job I'm walking about a lot anyway, it's exercise going steps up and down...I feel fine.’ [Indian woman age 33, 1602]

Other women mention exercise or sport as ways to keep healthy [13 women]. This is both active and passive. For example, 10 women identify exercising at home, six women say the walking they do everyday helps to keep them healthy. Two women try to walk rather than use transport in daily tasks in order to maintain health.

In contrast, eight women feel that relaxation is equally important to their health. The women identify watching Hindi films [3 women], listening to prayers [2 women], gaining enough sleep [2 women], massage [2 women], sauna [1 woman] and keeping warm [1 woman] as factors that help them relax and to keep healthy.

A strong theme to emerge from the data is that health maintenance is related to sociability. For example, many women are involved in self-help health related activities. Some value the opportunities provided by women's voluntary groups such as swimming [7 women], aromatherapy and massage [4 women].

Another important component of coping with health is the use and appropriation of spaces outside the home. Changes of space, going out and about and being with others, especially other women, are ways to keep healthy [8 women] and make women ‘feel better’. Some of the accounts are linked to the frustrations of full-time domestic labour and childcare and

patterns of mobility. One woman, for example, tells me that she 'feels fitter' since she has attended a voluntary group, as she gets out and meets people.

The data show that sociability and health are linked to happiness. This woman is typical of the seven women who emphasise that being happy is also good for health:

'... it's happiness is good for health.' [Pakistani woman age 27, 3101]

The women also emphasise the need to have and to keep personal space and time for themselves to enable them to stay healthy, but that this is not always possible. The use of other spaces is constrained by the obligations attached to gender roles and the absence of social support (see sections 3.6.1 and 3.5.2). The women quoted below both have preschool aged children. For these women, this means that much of their time is spent at home. These ideas arose in the context of discussion about health maintenance:

'...And I tend to go out a lot just to make myself happy and that makes me feel healthy, you know what I mean, if I am out and about. If I am stuck at home all the time I tend to feel miserable and that makes me think you know I am unwell really.

S.P.: Out and about doing?

I think that keeps me healthy.' [Pakistani woman age 23, 1301]

'INT.: She said when I feel better like when I go out, I go to the park, I go to mum's house and I feel better to do everything...' [Bangladeshi woman age 31, 2402]

I have shown that place is a marker for women's descriptions of health. Similarly place and lifestage affect women's descriptions of health maintenance. Two women perceive that their methods of maintaining health have changed since they have been married and had children. They feel freer to go out since they have been in Edinburgh, having moved from different English cities after marriage, and this enables their health maintenance.

Some women feel they want to do more in terms of their healthcare. They identify past healthcare strategies [5 women] or a variety of actions they would like to do to maintain health, in particular taking exercise [8 women].

Twenty three women link diet to their means of maintaining health. Their accounts support Stacey's (1988) argument that food preparation is extremely important in health production. The women are aware of the relationship between good diet and health and of healthy eating messages. Some women highlight the components of a good diet. They identify the importance of balanced diets [3 women] and talk about types of food that should be included

in or excluded from a healthy diet. They emphasise cutting down on certain foods like red meat [3 women], cutting out fats [3 women] and watching calories [2 women]. A vegetarian diet is important [5 women] as is eating vegetables [4 other women]. The women also identify a South Asian diet [1 woman] and eating 'well' [9 women], drinking water [2 women] and taking vitamin supplements [1 woman]. One woman volunteers that she knows she eats the wrong foods. The women also identify ways of food preparation as a means of health maintenance, for example, avoiding frying [4 women] or avoiding types of food preservation [2 women] to maintain the quality of food. In addition, five women perceive that having regular and proper meals is an everyday health maintenance action.

Dieting is also perceived to be a way to maintain health [11 women] as is avoiding over-eating [4 women]. For most of these women dieting takes place within their own routines. They emphasise eating less and limiting food intake rather than attending classes or using diet products. As noted above, about a third of the women are conscious of their weight. This shows again that women are keen to improve their health for the better.

'Health...I don't do anything, keep myself healthy I suppose I am eating all of the healthy foods that you can think of but not sort of conscientiously, I eat food to make me healthy you know.' [Pakistani woman age 33,1402]

These findings, however, do not reflect fully recent diet related health promotion messages and campaigns or targets issued by the Scottish Office (1993). Few women mention eating fruit to keep healthy, the consumption of complex carbohydrates or fibre, or the need to cut down on sugars. Although my study finds diet to be a central factor in health maintenance, it did not aim to ask specific questions about diet, rather it aimed to highlight women's healthcare concerns and actions as they saw them. Other studies support my findings on healthy eating behaviours. They show that so-called minority ethnic diets may be closer to correct nutritional guidelines than so-called western diets (Douglas, 1992). Further, they show that South Asians in Glasgow use brown flour more and eat sugary foods less than the general population (Williams, Bhopal and Hunt, 1994).

My findings on diet again challenge some of the stereotypical healthcare concerns in the literature. So called traditional South Asian ideas about food, for example, the *bhye bhaddi* concept (a cold disorder with excess production of mucus) discussed by Bhopal (1986a) or 'hot and cold' foods (a humoral concept that ill health may result from an imbalance of hot and cold) discussed by Donovan (1986) and Qureshi (1990b), are not to the forefront of

women's ideas about their own healthcare or diet. I would argue that their concerns and ideas are similar to those of other women.

It is not possible to be definitive about how women's ideas about health are constructed or whether they are in a position to implement health education ideas. McKie *et al.*'s (1993) work on white working class women shows that people's knowledge of healthy behaviours may not necessarily be translated into practice. Their work on food and health shows that women are bombarded with images of the body which presume that they can control their diet or undertake exercise and which promote denial and discipline to maintain body image. They also argue that the negotiation of diet occurs within the context of the family where a number of food preferences need to be balanced, where food preparation takes time, where certain foods may be unavailable and where 'healthy foods' may incur considerable cost. Landman and Wyke's (1995) study, however, on healthy eating among minority ethnic groups in Scotland found cost and availability to be minor influences on eating behaviour. All these factors may mean that women's own dietary preferences take on a low priority despite their key role in the management of family health.

This section has shown how methods of coping with and maintaining health are both everyday/passive and active. It has also revealed a number of constraints and enablements on access to sources of healthcare. In particular, the interview data reinforce a perception that health services are used in ill health rather than in health. They also show that women's access to sources of healthcare may be limited by a range of demands in their daily lives. In addition, the women interviewed are keen to gain knowledge about keeping healthy and knowledge of health education messages is widespread. I have argued that the health practices and concerns described above are not culturally distinct and many are shared with other women seen in the literature on women's health. Having considered how women keep healthy I will now discuss the issues raised in women's accounts of coping with ill health.

3.4.2 Coping with ill health

The accounts reveal the means by which the women manage and cope with ill health. It is not possible to differentiate between different types of ill health and compare the coping strategies used due to the nature of this study. In general, the women talk about ill health as an everyday experience and how they act in the face of such ill health. This is in line with Eyles and Donovan's (1986) definition of illness as an everyday phenomenon, which may

become a threatening or major condition. The accounts show that ill health involves disruption to everyday routines and this induces particular coping strategies which, I would argue, are common to many women.

One coping action in the face of ill health is to 'keep going'. This is also seen in studies focusing on white women (Popay, 1992). Nine women describe how they 'carry on' and ignore ill health totally or partially. This reaction must be seen in the context of the roles that women occupy in daily life. Ignoring ill health may also help women to avoid other detrimental effects on well-being caused by an episode of ill health. For example, keeping going is one way to cope with feelings of frustration induced by inactivity when ill [4 women]. The following account provides a good example showing how women ensure that everyday life continues despite their ill health:

'S.P.: Can you tell me about the last time that you were ill?

Well put it this way I am just in the middle of a cold right now. What I have been doing is just not going anywhere the past two or three days and just sleeping, feeling very tired. I have been trying to catch up with the housework which obviously is not resting although I am at home but...

There's times like for instance I was feeling ill, I don't want to get up early in the morning, get the children ready for school. I feel as though like if I left them at home I would feel a lot better because I would be at home and I wouldn't have to go in and out. But then I changed my mind I think it's better if I do take them so obviously I can rest and do what I want to do in peace and quiet. So that is this morning I don't literally want to go out at all. But I took them and I am glad I did.' [Pakistani woman age 23, 1301]

When discussing their actions in ill health eight women stress that they have 'never been that ill'. This type of statement is related to the need to define oneself as healthy as argued above. Keeping going may allow women to feel that they are not ill. This woman clearly does not want to label herself as ill and keeps going:

'...But I did all the housework, still I wasn't well...To do little things when you are bad to give you some confidence that you're not so very ill. You don't feel that you're so bad, I mean you'll get over it. And it keeps your mind busy not thinking about illness all the time... I don't lie down all the time, I do my work.' [Pakistani woman age 54, 2104]

The woman quoted above shows that the practice of ignoring ill health totally or partially is assisted by dividing ill health according to the gravity of the health problem. The quote also shows that this division has implications for help seeking behaviour. This is discussed in section 4.4.2.

Another coping strategy is to avoid certain practices known to exacerbate ill health. Worries or thinking about health problems too much is seen as a catalyst for ill health [3 women]. This finding is supported by Dickinson and Bhatt's (1994) work on attitudes to health among South Asian, Chinese and Afro-Caribbean respondents aged 35-65 in England, which found that too much thinking about health was unhealthy. Keeping going may be a way to avoid worrying and so to avoid exacerbating ill health. Some women negotiate this worry by talking to others and this helps them cope with ill health. For example, this woman describes the help she is given by her health visitor (other dimensions of social support are considered in section 3.5-3.5.2)

'S.P.: How does she [health visitor] help you?

Basically just by talking you know, letting me know not to worry too much. That helps sometimes. If you don't know what it is exactly and then you just worry and get yourself ill and that way she just helps you know, it'll be all right whatever.' [Pakistani woman age 23, 1301]

For most women initial coping strategies in ill health take place outside health services. When the women were asked directly in the interviews questions like 'what do you do when you get ill?', only two women volunteered that they would go to the doctor first. This theme is added to in the next chapter. Coping strategies outside health services are shown by nine women who identify long term health problems such as anaemia, ulcers and asthma. These women manage their health problems by monitoring their health, pre-empting the problem and taking measures to lessen its impact or to prevent the problem surfacing.

Many of the women's actions in ill health mirror those used to maintain health. Again coping with ill health takes place in the context of women's everyday lives. Measures include using over the counter medicines [10 women], keeping warm [4 women], having drinks [5 women], having peace and quiet and allotting time to recover [2 women], staying inside [3 women], religious observance [2 women] and relaxation. Fourteen women identify rest as a means to overcome health problems and 'rest it out', though two of these women feel they will only rest if they feel particularly 'bad'. Other relaxation techniques involve watching Hindi films [2 women] or television [1 woman] which allow you to 'take your mind off things' when unwell.

Other self-help actions include the use of home remedies [16 women]. These are prepared from ingredients found at home by the women or their mothers. During the interviews some women showed me the ingredients that they use in remedies. Five women feel that they do

not use home remedies as much as they would like, as they are unable to get the required ingredients in Edinburgh. Seven of the 16 women say they use home remedies because they do not have side effects.

The women also cite the use of complementary medicine as a coping strategy in ill health. One woman feels that she would like to use more complementary medicine, but that cost is a consideration. Massage [7 women] and aromatherapy are identified by a number of women. These therapies are provided by two of the voluntary groups I had contact with, though only three women volunteer that aromatherapy is a practice that they use to cope with ill health. Five women use homeopathic medicine in ill health. Two of these women have brought it back from the Indian subcontinent to be used when needed. Like home remedies, they feel that this type of medicine has less side effects.

In the main, the women use mainstream health services rather than other forms of medicine. The accounts raise a number of points around this theme. The evidence suggests that firstly, complementary medicine is used in parallel with, and does not affect, mainstream health service use. This supports Bhopal's (1986a) assessment of interactions between South Asian and Western medicine. Secondly, many of women's uses for home remedies mirror the small health problems defined by the women which allow them to carry on in the face of ill health as argued above or the small health problems that are perceived not to necessitate a GP visit (see section 4.4.2). The use of home remedies is also identified in work focusing on Afro-Caribbean groups (Thorogood, 1988, 1983; Morgan and Watkins, 1988; Donovan, 1986), on Pakistani women (Bowes and Domokos, 1993) and on majority ethnic women (Stacey, 1988). It is, therefore, not particular to South Asian women or to minority ethnic groups. Thirdly, other forms of treatment, for example, private medicine are only suggested by three women and are connected to women's ideas about the demise of, and constraints imposed on, the NHS. Private medicine is seen as a way of gaining better or faster treatment, however, again cost is a major consideration.

It is often suggested that minority ethnic groups make greater use of traditional or alternative medicine. A particular research focus has been *hikmat* therapies (a Graeco-Arabic system of medicine) practised by *hakims* especially among Indians and Pakistanis (Aslam and Healy, 1983). Much work focuses on the peculiarities of South Asian health behaviours and concepts of health focusing on hot and cold food, particular ailments and bodily conditions. Beliefs about South Asian patients use of and reliance on *hakims* have become 'part of the

established medico-sociological folklore' about South Asian health practices (Ahmad, 1992: 526). *Hakims* are seen to be potentially dangerous to health and users are criticised for their 'unscientific health beliefs' (Howlett *et al.*, 1992: 282). It is implied that western medicine is 'rational, scientific and safe' while other forms are not (Ahmad, 1992: 530).

Again my findings challenge the stereotyped health concerns of South Asian women. My study shows that so called 'traditional medicine' is not central in women's own accounts of coping with ill health. My findings are supported by other studies: for example, Johnson *et al.* (1983) and Jain *et al.* (1985) who report only low support for traditional medicine among South Asians; by Ahmad (1992) who suggests that the use of alternative practitioners among South Asians in the UK is very low; and by Smith's (1991) study in Scotland which shows that 97% of minority ethnic and 98% of white respondents would use the GP in the first instance for check-ups or medical treatment.

In the last two sections I have argued that women negotiate healthcare from a number of sources including other countries, family members and the voluntary sector. I have shown that the women negotiate healthcare in a number of different arenas and indicated that patterns of healthcare in this arena may affect patterns of health service use. These findings support my argument that access to healthcare is more than the use of health services. The analysis shows that South Asian women are not fatalistic about their health, as shown in other studies (Donovan, 1986) and are active in their own healthcare. The health behaviours highlighted in health and in ill health are both curative and preventative, active and passive. I have shown that the women are keen to maintain, improve and care for their health, to gain information about health and that they are receptive to health promotion messages. I have highlighted links between sociability and health, for example, the use of space outside the home which is identified as an important aspect of keeping healthy. The next section focuses on the issue of social support and access to healthcare in this arena.

3.5 Social support and access to healthcare outside services

Above I argued that health is linked to sociability. The women show how help from others is involved in their patterns of healthcare and influences their healthcare experiences. The literature shows that there is broad agreement that something called social support exists in coping with life events (Williams H. A., 1993), however, the concept of social support, has been interpreted in several ways (Shumaker and Hill, 1991; Turner *et al.*, 1983). Bowling

(1991: 69) describes it as 'the interactive process in which emotional, instrumental or financial aid is obtained from a social network'. Social support then focuses on the helping elements of human relationships.

The concept of social support continues to be poorly understood for minority ethnic groups. The literature shows that for South Asian women, access to and emphasis on non-professional help and support is often assumed (Carby, 1982; Parmar, 1982). One focus of debate has been the importance and existence of the South Asian extended family and the commonly held view that South Asian families 'look after their own' and are reciprocal in providing support. Studies show that such assumptions have implications for South Asian women's experiences of health services (Bowler, 1993a, 1993b; Evers *et al.*, 1989) (see below). The extended family invokes stereotypes of minority ethnic culture and is little supported by empirical evidence (Bowler, 1993a, 1993b). Assumptions of the role of the extended family, however, act to smokescreen an examination of the nature and role of social support in healthcare and the need for social support among South Asian groups.

The importance of social support in explanations of patterns of health and healthcare is unconvincing. Most studies consider health status and social support and use measures of the frequency and type of social contact without a deeper analysis of the quality of social support (Bowling, 1991) or without an analysis of people's experiences of, and perspectives on, social support and healthcare. For example, Williams *et al.* (1994) found that Punjabi respondents in Glasgow had lower levels of social support than white respondents, but that levels of social support did not correlate with self-reported stress levels which were equal for both groups. On the basis of limited evidence about the effects of social support on South Asian women's patterns of healthcare my argument is that studies need to investigate social support and its effects on healthcare without assuming its existence or how it works. A broader conceptualisation of access to healthcare is therefore relevant.

Studies show that the assumption of the South Asian extended family has implications for service provision and for understanding access to healthcare. Connelly (1988) and Evers *et al.* (1989) link assumptions about the extended family to the nature and extent of service provision. According to Connelly (1988) assumptions about the existence of the extended family and a commitment to care for older generations may be taken to mean that service provision need not concern itself with minority ethnic groups. In addition, this myth may mean that there has been little change in services to cater for minority ethnic needs. With

Atkin *et al.* (1989) I would argue that the existence of the extended family cannot be assumed, nor can it be assumed that family carers do not need support from services. The question we should be asking is not whether the extended family exists but whether services meet the needs of minority ethnic groups.

Few studies address social support and minority ethnic groups' patterns of healthcare. My review of the literature draws a number of further conclusions. Firstly, there has been little work on the links between social support and access to health services. Notable exceptions are studies by Donaldson (1986) which shows that low uptake of community services by minority ethnic elderly people is affected by patterns of informal home care, and Nelson's (1993) study on African-American elderly people, which shows that social support affects rates of health service use. Secondly, there is little work on the experience of social support among minority ethnic groups. Studies by Atkin and Rollings (1992) and Atkin (1989) on Community Care provide useful insights into and debate about the nature of informal care among minority ethnic groups. These studies note the invisible nature of care giving among black carers. Finally, few studies focus on social support as defined by South Asian women themselves. Nelson's work (1993), for example, uses predefined measures of social support to determine effects on health service use. I would argue that this is problematic given that social support continues to be poorly understood for minority ethnic groups. Approaches must be more open to conceptions of social support defined by, in this case, South Asian women. This will go some way toward challenging stereotypical understandings of the operation of social support for these women.

For conceptual reasons it is useful to distinguish between types and sources of social support. My findings focus on self reported data examining who provides what assistance in health and ill health in this healthcare arena. This is in line with my conceptualisation of access to healthcare. In general my findings consider perceived rather than administered social support. They are exploratory and must be considered with some caution, though they do indicate scope for further work. My findings do not include measures of the extent of social networks, the intimacy of relationships or the frequency of contact, although it must be remembered that extent does little to indicate the experience of social support. Rather, my findings focus on the everyday experience of health and ill health in general terms. The aim is not to examine social support and link it to health status. This is in line with my argument to shift away from disease centred research outlined in chapter 1. Although different types of social support have different effects according the nature of a

health problem, my findings cannot account for the variability in experience of social support according to health status. My focus on the general experience of social support is supported by Williams' H.A. (1993) work on social support and parents of black and white chronically ill children which shows that parents generalise their responses to questions about social support despite differences in the extent of their child's ill health.

3.5.1 The role of social support in access to healthcare outside health services

The interview data suggest that social support plays a number of roles in women's healthcare outside health services both in ill health and in health maintenance. These are educational, psychological and practical. My findings also suggest that patterns of social support are linked to access to health services. For analytical purposes I have divided the type of social support in ill health into two types, the routine care provided day to day and other incidental or occasional forms of support.

It is my impression, from a systematic review of the data, that some women find it easier to identify the role of social support in ill health than in health, as these quotations show:

'S.P.: Is there anyone else you would like to talk to about your health?

Nothing I am not ill you know. No need to talk.' [Indian woman age 59, 1504]

'INT.: In the family they don't talk about the little sickness like temperatures or some things like that if it's serious *beemar* [diseases]...then people discuss about it and talk about it, but they don't talk about general health or anything like that.' [Pakistani woman age 30, 0501]

The women were asked who they talked to and confided in and who provided support in health and ill health. In health and in ill health, the women highlight the importance of care provided by other women both inside and outside the family (Table 3.1). The findings suggest that for some women, gender networks of care, that is care provided by other women, stretch beyond local relatives and friends to other parts of the UK or beyond.

Thirty four women identify family members who are seen to provide support in ill health and 16 women cite people outside the family. Table 3.1 shows that the sources of everyday social support the women identify in ill health are not necessarily the same as those who provide other types of incidental support in ill health. The findings suggest that female friends are more important in incidental forms of care than everyday care in ill health.

Provider of social support	Health maintenance	Everyday social support in ill health	Incidental social support in ill health
Female friends	13	1	14
Husbands	8	20	17
Children	0	11	10
Mothers	5	0	3
Sisters	6	2	6
Sisters-in-law	3	0	5
Daughters	2	0	0
Daughters-in-law	3	2	2
Mothers-in-law	0	2	2
Parents	1	2	3
Sons	1	0	0
Linkworker	1	0	3
Family more generally	1	0	0

Source: all interviews (n=36) Note: columns refer to number of women who gain support from each source.

Table 3.1 Sources of social support identified in women's healthcare outside health services

The evidence suggests that the locus of day to day care in ill health is the immediate family and to a lesser extent those who are nearby. From a systematic review of the data it is my impression that the main responsibility for day to day care rests with members in the household, usually husbands and children and that friends provide episodic support, for example, helping with work around the home. In addition, other family members may only become involved if a health problem is serious, if recovery takes some time or if support is requested. All but seven women had relatives in the UK though it is not possible to say how many lived close-by. In ill health, the social support provided by other women is highlighted as especially valuable. All but three of the 36 women mention the importance of help from other women both inside and outside the family. Only four women mention men other than husbands, as sources of social support in ill health. Three women identify fathers. The women describe how husbands: provide health advice; take over some of their daily tasks, particularly those inside the home; or bring home food, especially if they work in the catering industry. Pershad and Tyrrel's (1995) study on South Asian women in East Pollokshields, Glasgow, also found husbands to be the main source of practical support in the home in both antenatal and postnatal care. In contrast to my findings, their discussion shows that help from women friends and relatives was mentioned by only a few women. My findings and those of Pershad and Tyrrel (1995) challenge the tendency of explanations of South Asian women's health behaviours and needs to draw on the idea of the extended family.

In health, the women also discuss some areas of non-GP primary healthcare as sources of social support in health maintenance. This arose in the context of questions about health maintenance, coping with ill health and learning about health and healthcare. Two women identify health professionals such as the GP, and another three women identify linkworkers as sources of social support in health. Eight women comment favourably on the role of health visitors in their own healthcare. Some reveal that they are still in contact with health visitors they have seen in the past. This finding is in contrast to other studies on minority ethnic women. For example, Larbie (1985) found that the young Afro-Caribbean mothers she talked to were sceptical about the role of health visitors and that some expressed needs were not met by health visitors.

In my study the women's reasons for their favourable comments about health visitors are rooted in communication. The women who talk about health visitors feel that the health visitor listens and has time to speak to them. This enables women to approach the health visitor even with small problems when s/he comes to see her children. Others feel that they gain more information from the health visitor compared to other health professionals and feel able to approach him/her with particular worries about their health, as well as actual health problems. The interaction between South Asian women and health visitors certainly requires more investigation (see Bowes and Domokos, work in progress, Stirling University).

Social support and information

The first role of social support in the women's healthcare in this arena is the provision of health information. As noted above, the women are open to health ideas and are keen to expand their knowledge. They are both sources of and receptive to health education messages. Two women say that they are sources of health advice for others. In ill health, social support assists with ideas and actions to cure ill health. Nineteen women share health advice about their health worries or problems. Three of the 19 women identify the importance of others in discussing the type of medicine or home remedy to take. Five women volunteer that ideas about home remedies have been passed on from mothers and grandmothers.

The manner in which health advice is given is identified as an important aspect of this type of care. Three women pinpoint the value of tackling health worries or problems with other women in an informal setting:

‘...we tend to have sort of like discussions with my friends and that, maybe talking about something maybe health will sort of creep in...’ [Pakistani woman age 23, 1301]

Informality helps to diffuse health worries and to lessen negative feelings and any stress that may be associated with health problems. It allows women to take health worries less seriously, to discuss health problems and to avoid worries about health which, as shown above, may exacerbate ill health. In health, the women stress the value of what might be called more ‘everyday’ means of learning about health and healthcare through personal relationships. This leads to a sense of everydayness and common-sense about health knowledge. Some women feel that ideas about health maintenance have ‘always been in their minds’ [2 women] or are part of common-sense [3 women].

In health, women receive healthcare information from a range of sources, not just health professionals. According to Foster (1995) people have access to more information about medical matters today than they have had at any time this century. Most women identify non-health professionals as sources of health knowledge [31 women]. There is little mention of health promotion materials to assist with general health [2 women]. Health ideas are gained from family in childhood or when growing up, for example, through school [4 women], also from books [4 women], women’s magazines [3 women], colour supplements [1 woman], from the television [8 women] and from health and exercise videos [1 woman].

The accounts indicate that ideas about health and healthcare are gained through social relationships. For example, one woman feels that she has increased her knowledge about health issues since she has been caring for her mother-in-law, who has health problems, another cites a health course that she had attended. This woman talks about learning about health issues at school:

‘...learning different people’s ideas, you know what people around you are doing. And you can see for yourself their lifestyles are so busy...Asian women I think it helped them going shoulder to shoulder with them. I mean going to school for instance my generation mixing with different nationalities.’ [Indian woman age 33, 1702]

Some women identify sources of health advice that stretch beyond local relatives and friends. Family members in the UK and abroad are also used as a source of healthcare ideas. This woman is typical of three others who feel the support provided by other women to be particularly important as their families are not in Edinburgh:

‘S.P.: How do they help?

They [female friends] tell me they heard from relatives and the other friends so they tell me and if I heard from my husband and my relatives I tell them...’ [Pakistani woman age 27, 3101].

Non-professional support allows women to increase their health knowledge in their everyday lives. Fifteen women identify others as sources of advice about health maintenance. Included are female relatives [8 women], female friends [7 women], husbands [5 women], linkworkers [1 woman] and sons [1 woman].

The following case illustrates the role of non-professionals in providing health information. This woman contrasts the health advice that she gets from her GP with the advice provided by others i.e. non-health professionals:

‘When you go to the GP you have this certain...something specific or particular then you go. But when you are sitting discussing about health you just pick up things from and you don’t discuss things like that with your GP, you know what people should be eating and what they shouldn’t be...some other woman she’s got back trouble and she’s telling you what she does because of back trouble, precautions she takes. So maybe in the future if you’ve got back trouble I keep it in mind...So that’s why I think it [talking to others] helps.’ [Sikh woman age 37, 0202]

Social support and psychological help

The second role of social support in healthcare is the provision of psychological support. This woman describes how she and a friend help each other in maintaining their health:

‘...the two of us will decide together, right we are going to start or diet...the both of us in the same position and we help each other. If there’s something on my mind I can go and talk to her even if it’s something stupid... she will actually listen to what I am saying...’ [Indian woman age 33, 2002]

As noted above, mental well-being is an important aspect of keeping healthy and is linked to sociability. Eleven women feel the support of others helps them to rationalise their health worries, allay loneliness, and to increase well-being. The evidence suggests that women friends are associated with happiness, and this, as noted above, is linked to health. The accounts suggest that the voluntary sector plays an invaluable role in the everyday health maintenance of women. Four women appreciate not only the provision of dieting and exercise classes by voluntary groups but also the sociability that they provide. This woman attends a group for the over 50s:

‘INT.: ...when she mixes with other women that was there from different cultures and that so she feels really good. Like when she mixes with other women, she feels at home with them in a sense...’ [Sikh woman age 67, 1204]

Another woman talks about the support provided by her sisters-in-law and daughters-in-law and links it to her well-being:

‘In a way I feel it’s helped me stay healthy as well and that because we have got a lot to offer each other...helping each other physically as well as mentally in a sense you know. We can talk to each other about our problems and that. There’s a lot of women who can’t...they keep their problems to themselves.’ [Sikh woman age 44, 0703]

The accounts distinguish between types of social support. Some women feel that they need more passive social support to allow them to talk about their health [3 women] and that this would contribute to their well-being.

Social support also plays a valuable psychological role in ill health. This finding is in opposition to other studies on minority ethnic families. Williams’ H.A. (1993) study found that white parents emphasised the role of psychological support provided by others more than black parents (the ethnic background is not specified). For the majority of black parents, being supported meant receiving instrumental assistance, for example, help with transport, money or shopping. In contrast, my study shows that talking about health problems and health worries is valued by the South Asian women interviewed. Fourteen women highlight the psychological support provided by others who express concern and empathy. For example, four of these women feel that talking to other women who have been through the same health problem or experience helps them to ‘feel better’. Two other women appreciate it if others ‘look out for them’ and their health problems or if others remind women to use health services. Above I have argued that sociability is important in health maintenance, similarly four women feel that time spent with others is important in ill health and encourages better health as these quotations show:

‘I feel better if I have somebody to talk to about it [health problem]. When you are lonely, you feel poorer, sick, if you’re very ill and if you talk to somebody you feel light.’ [Pakistani woman age 48, 1803]

‘...I would discuss with my sisters and C. [female friend] because that way you can release you know all that kind of tension, all that pressure that you have got a problem. And you can’t express it to anyone so by releasing it to someone like C. or my sisters I feel better...It makes you a bit healthier than keeping it cooped up inside.’ [Pakistani woman age 33, 0302]

Social support and practical help

The final role of social support in South Asian women's healthcare is the provision of practical assistance. In health, this includes helping women to avoid things that might compromise good health or exacerbate existing or long term health problems. For example, one woman appreciates the help inside the home given by her daughter-in-law as this reduces the likelihood of exacerbating her asthma. In this case social support reduces the likelihood of changes in health state and acts as a buffer for ill health.

The practical help given by social support in ill health includes help to harness different health services. Two women identify the financial role of others in harnessing private medical care or complementary medicine. The evidence suggests that the practical role of social support in ill health extends beyond the use of others to provide language assistance identified as a key factor in access to healthcare for South Asian groups. The women emphasise the practical assistance of others in their health actions for example, getting medicine [6 women] or massage in ill health [3 women]. Nine women identify the personal care provided by others who do simple tasks such as bringing drinks or making tea.

Social support enables women to have some personal space away from daily tasks, such as work inside and outside the home. An important aspect of coping with ill health involves help with the family, tasks around the home or 'helping out' [25 women]. Fifteen women value having someone else look after their children. Two women feel that others help them by reducing their tasks at work in family businesses. The evidence suggests that social support reduces the pressures of simply 'carrying on' in the face of ill health. This woman remembers coming home after the birth of her youngest child a few months earlier:

'You know when I came from hospital in this time yes I can't do anything because I have problems in pain back yes. So my friend came the next day in the morning to me and she done everything, cooking and changing clothes my kids and hoovering and like that things and give me my clothes and you know force me to take time [for herself]. This is the help so good thing, you know Asian people feel Asian people's problems and like and help I think we take help, Asian peoples.' [Pakistani woman age 27, 3101]

She feels that she is only able to gain help from other South Asian women because she feels excluded from the wider environment and from health services. This leads her to feel that 'only Asian people feel Asian people's problems'.

Another woman remembers being ill in India but recounts her feelings about the practical support provided by her family there:

‘if you are on your own [in the UK] there are things that you have to get on with housework, you know that the kids are coming home even if you are feeling a little down you still make an effort to get up and do it. Whereas [in India] with the extended family all the time...I didn’t have that kind of pressure on me.’ [Indian woman age 33, 1702]

Some women specify that they need more of this type of social support, including help with children both in health and in ill health [8 women] and help around the home [6 women]. Three volunteer that they need more linkworker support to assist in this healthcare arena.

As noted above, in ill health the women’s accounts link social support to their patterns of access to health services. The relationship between social support and health service use is complex. My study, though exploratory, provides evidence to suggest that social support is used in response to women’s perceptions and experiences of health services. The negotiation of healthcare, therefore, stretches both outside and inside health services. This finding also supports my argument that healthcare must be considered in its broadest sense beyond health service use.

Links between social support and health services

The use of social support in relation to health services occurs for a number of reasons which are outlined below. Firstly, the evidence suggests that it is used in response to constraints on choice in health services. This makes some women turn to social support more readily than they otherwise might do. The woman quoted below feels that she wants to see a woman GP about her period problems. She describes the social support that she gets from her sister and links it to her inability to exercise choice inside health services:

S.P.: Do you talk to anyone about your health?

Yes, sometimes to my sister, nobody else aye just my sister.

S.P.: Why your sister?

[She’ll say] have you had your periods and she’ll say it’s just your age now maybe that’s why [you are having these problems]. Sometimes I don’t even ask my doctor. We’ve got two men and a woman and sometimes you can’t get doctor, like use the doctor lady. I say all right doesn’t matter, I’ll get doctor the man and you just get embarrassed, you don’t like to talk to him. If it’s Doctor A. I talk to the lady doctor about everything, she’s very nice and she listens to me, sometimes heavy period [periods] or anything like if it’s I can ask her.’ [Sikh woman age 42, 0903]

Secondly, social support may be used in response to perceived constraints in health services. Some women are concerned that they might appear foolish, appear badly or be condemned in front of health professionals or that health professionals may not listen to or dismiss their concerns. One woman perceives that her GP would not listen to her concerns and would avoid her questions. In response she turns to her friend because, in her words, she can 'trust her'. The woman quoted below expresses her feeling that she might not be taken seriously. In the interview she discusses the support that she gets from a few close women friends:

'You could always I guess turn to your doctor and that but it's not as serious to talk to a doctor about it really. A doctor would think I am stupid because obviously I am not that overweight or anything...' [Pakistani woman age 23, 1301]

Thirdly, social support may be used when women's health service interactions are perceived to have failed. For example, if a woman feels that a health professional has been non-supportive or that her relationship with a health professional is unsatisfactory (see sections 4.3.3 and 4.4.1).

Fourthly, social support may be used because women feel, from past experience, that they are unable to make use of health services, such as the GP, effectively. This woman describes the trust and relief she feels when she is able to talk to someone about her health in her own language. She feels that she is able to explain everything:

'INT.: She can explain to S. [woman friend] herself you see and it makes her lighter, more lighter because she can't speak English to the doctor.' [Bangladeshi woman age 27, 2701]

Finally, social support helps women to harness health services. The accounts are rich with the experiences of women where non-professional help and support is used as a response to difficulties faced by women inside health services. Further evidence for this is included in chapters 4 and 5.

This woman speaks little English. She uses a known and trusted linkworker to help her harness health services. Her previous negative experiences reinforce her need to use a linkworker when seeing the GP. The linkworker helps her to combat what she feels to be negative staff attitudes towards her and helps to ensure her access to the GP. In the interview this woman is very keen to tell her story which arose when discussing her health:

'INT.: She feel comfortable with me [linkworker] like her mother and she hasn't got any what's it called? She can [be] free with me, she can speak everything to me about her

problem, if she got problem then she can speak with me... [she] feels like I am her older sister.'

'INT.: She call me [linkworker] and I take her to the doctor I explain properly but if she go herself and she try to explain and she feel like doctor [does] understand but is... they are pretending they don't understand her problems...' [Bangladeshi woman age 31, 2402]

The material suggests that social support may be used to overcome constraints in health services such as women's lack of choice or communication difficulties. This woman feels that she needs someone who is 'like her' or 'like her mother' to counter the exclusion that she feels when seeing the GP. The next section examines constraints on the use of social support in the healthcare of the women interviewed.

3.5.2 Constraints on the use of social support in healthcare outside services

The women's accounts reveal a number constraints on the use of social support in women's healthcare and instances where non-professional help is not necessarily supportive, useful or available. These findings are important as they show that social support has some limitations. Again women's experiences and views provide evidence to challenge the existence and role of the stereotypical support network in South Asian women's healthcare.

Good communication is an important aspect of the healthcare provided by non-professionals as well as professionals. In this healthcare arena 10 women stress the ability of others to listen and to respond sympathetically. Four of these women feel that others sometimes do not listen and that this dissuades them from using particular sources of social support that might otherwise be open to them. Six women feel reassured that they have people with whom they feel able to discuss healthcare issues and that others would be there to help if needed [2 women]. Three others feel that others speak of their 'bad' experiences in attempts to provide support, or do not listen to their healthcare concerns, and that this constrains their use of social support because it might lead to worry or confusion. Other aspects of communication identified revolve around the ability of others to understand [4 women] or to take their concerns seriously [2 women]. Finally, this woman is typical of six others who feel that language problems constrain their opportunities for using social support to enhance healthcare and well-being:

'INT.: She hasn't got anyone to talk to. People are all around me but where will I go to speak. I can't speak.' [Bangladeshi woman age 64, 2604]

A lack of 'closeness' may also constrain social support in women's healthcare. Trusting a person [7 women] and 'knowing' someone [10 women] are both positive aspects of social support and are linked to good communication. Six women feel that they turn to certain significant others because they feel that they 'are a priority' for them or that others are able to 'think for' them. Trust is another important theme identified. Four women stress the need to keep their discussion with sources of social support confidential, and that this is especially important given the social networks among the small South Asian population in Edinburgh.

Another theme affecting the use of social support in healthcare is 'similarity' between people [13 women]. The accounts suggest that agreement or identification with a person's beliefs or feelings is important. Three women, for example, feel more able to gain social support from family or from those that are 'your own' or 'whose habits or thinking are the same'. The woman quoted below describes the social support given by close friends and her husband:

'Because I realise when I take advice from them [women friends] it's good for me and when I take advice my husband so is this, because this is our family...and other peoples give me advice so it's not, you know it's...they [friends] are not taking very, really much seriously than us.

S.P.: They don't take you..?

...I feel you know the other people not giving the right advice they just give, they just say do this, they don't, you know *thinking clearly and deeply for us*. Yes so that's why I don't want to talk to them about my problems because I think they *do not share with me* you know I just depend on my husband and he depends on me...' [Pakistani woman age 27, 3101] [own emphasis]

The next case illustrates the importance of good communication and trust in the provision of social support in the women's healthcare. This woman emphasises the value of social support gained from 'her own' i.e. those who are close to her, and contrasts this by describing the social support she might provide for others who are perhaps not so close to her:

'Sometimes people don't like to listen to you. If somebody talks to me I listen, I say do this do that but I feel...'what is she telling me for?' If it's *your own* you don't mind telling the truth...Everybody's got their own problems, you can't talk to everybody, yourselves...I help her [sister-in-law] she helps me when we talk [it] out you know...sometimes you can't trust people sometimes people laugh at you if you say that I am on heavy [period] or this happened or...' [Sikh woman age 42, 0903] [own emphasis]

Similarities in life experience are also important in enabling access to social support to help with healthcare. For example, six women feel that they gain the most useful social support from those who are of a similar age. Five women emphasise similarities in ethnic background and life episodes [3 women], life experience linked to shared gender [2 women], or health experiences [3 women] enable the use of social support.

‘Because her age and my age the same...her ideas and my ideas the same.’ [Bangladeshi woman aged 28, 2501]

In the interview this woman describes a physical health problem caused by worries about her husband’s long periods away since their marriage. Here she is grateful for the support provided by another woman who had been through the same life experiences:

‘Like I say I used to get help [from other family members] what I needed at the time was words and them words wasn’t right from my mother-in-law ’cos she hadn’t been through it. So I went to that person who had really been through it...’ [Sikh woman age 23, 1901]

The interview data suggest that opportunities for using social support are affected by gender role obligations and by physical distance between people. Ten women volunteer that the social support provided by other women who are close by, is particularly valuable. The case quoted below is typical of 17 others who feel that social support is limited by people’s busy lives. For three women, this leads to feelings of guilt about the social support that they have received in the past:

‘...That’s all you know sometimes family, you know everybody is busy [with their families] and you know like life here is busy life and everyone busy at home so you can’t tell everything, you know [to] relatives, and you have to solve your problems by yourself. I just share with my husband.’ [Pakistani age 27, 3101]

Four women feel that others will worry too much if they ask for help with healthcare, especially if others have their own problems [4 women] or families [3 women]. This woman expresses reservations about telling her family of her health problems because she does not want them to worry:

‘...I don’t like telling what’s wrong with you, everybody’s got their own problems, it’s one of these things... all my family never knew. They knew I got bad flus and colds quickly but I didn’t tell anybody I’m asthmatic...Because they worry for you...’ [Sikh woman age 42, 0903]

An indication of the value of social support can be seen if we compare it with those who miss the support that has been available to them in the past. Seven women miss the support

provided by others, for example, family who are in other parts of the UK [7 women] or in the Indian subcontinent [4 women]. They also miss mothers [4 women], fathers [1 woman] and daughters [1 woman]. Six women describe the social networks and support that they have left. Two of these women miss, in their words, 'having people around.'

'...I think I miss the fact that I don't have the family around you know like to come and see the children and things like that... I think you know like you see your friends like they have all got their family and so on. They come round and talk about their families and I feel slightly left out...' [Pakistani woman age 23, 1301]

The interview data show that even where social support exists, women's opportunities for accessing it are affected by several factors. Some feel that they only ask for help from others in emergencies, or that their families are not always available or necessarily the chosen option all the time. This suggests that we cannot assume the existence of or role of social support in an individual's healthcare. I conclude that social support, like health itself, is a matter for negotiation and cannot be assumed for South Asian women.

Social support plays a number of roles in the women's healthcare. These are psychological, educational and practical. Social support for South Asian women in health and ill health is more than just interpreters or culturally stereotyped extended families. My findings show that social support for South Asian women needs to be conceptualised in broader terms than conventionally thought. The literature on minority ethnic groups focuses on patterns of support primarily provided by kin and on family behaviours. This is in contrast to work focusing on the majority ethnic population which takes a broader view of social support and includes more categories of people (e.g. Oakley, 1992; Oakley and Rajan, 1991; Bowling, 1991). My findings show that social support is important in ill health and in health but that it is other women, including those outside kin networks, especially friends along with partners who provide significant support in women's health maintenance and in ill health.

This analysis also challenges the existence of, access to and use of, the extended family in South Asian women's healthcare. Even where the archetypal extended family exists, it does not necessarily play a key role in women's healthcare as conventionally thought. Social support has a number of limitations. It is constrained by factors including gender role obligations, constraints on communication in its broadest sense, and physical distance between people. It is also enabled by similarities between women. I have shown that social support assists healthcare both outside and inside health services. One of the most

important findings is that social support is used in response to healthcare provided by health services.

3.6 Collective factors and access to healthcare outside services

Sections 3.6.1-3.6.2 examine the broader structural issues which affect South Asian women's access to healthcare in this healthcare arena. I use women's perspectives on and experiences of healthcare to show that ideas about 'race' and gender difference are integral to women's healthcare experience, attitudes to healthcare, and their health actions in this healthcare arena.

3.6.1 Gender dimensions of access to healthcare outside services

This section considers the gender dimensions of access in the arena of healthcare outside health services. Gender dimensions of access build on my analysis of the factors affecting access to healthcare described above: themes include the ability to have and to keep time and space for oneself, deference, juggling multiple roles, isolation and links to social support. All these factors affect women's access to healthcare in this arena.

Health attitudes

My findings suggest that gender role obligations affect women's assessments of their own health, orientation to their own healthcare and their health and well-being. Eleven women feel that the multiple roles they occupy both inside and outside the family, affect their health and well-being. Tiredness and weight are two of the most frequent conditions referred to. In the interview this woman talks about her experience of stress. She feels that she needs to be healthy to fulfil gender role obligations but at the same time feels her position in the family contributes to her experience of stress:

'It's a major point you have got to be right in the head when you're looking after the kids and running the home and everything. Hell of a job I think. People don't realise the things a woman puts up with. I suppose a man does in a way but I think all women suffer...' [Sikh woman age 31, 0602]

The social roles that women occupy affect their attitudes toward their own health and healthcare. The data suggest that women's individual health is seen in the context of others and their needs. The findings illustrate the sensitivity of women both to their own and other people's health needs. Their worries about their own health and healthcare, for example, are

meshed with concerns about the well-being of others. They are also expressed in relation to the social roles that they occupy. Health is experienced and talked about within the context of the family, work and home life. Six women's descriptions of their own health include their concerns about the health of certain family members. This illustrates the 'unpaid health worker' role (Stacey, 1988) played by women in the family and their role as maintainers of good health. The women describe why they need to be healthy. Their health is not only important for themselves. Some women also feel that they need to be healthy so as not to worry others particularly those who are some distance away in the UK or in the Indian subcontinent [3 women]. Eight women feel that they need to be healthy for their children. The woman quoted below is typical:

'INT.: Generally I am quite healthy person, don't have too many problems. I think myself quite healthy. Once you are married and once you have small children in the house you have to be healthy.' [Pakistani woman age 30, 0501]

Paradoxically, having children both enables and constrains women's own healthcare actions. This illustrates a contradiction between the need to be healthy and the ability to act on health and ill health as highlighted in my discussion on diet (section 3.4.1). If the women have children, a common theme is to be healthy 'for them' but at the same time gender role obligations may constrain women's healthcare actions and opportunities. In the interview this woman mentions the importance of listening to her needs and acting on them. She then links her state of health and her responsiveness to her health needs to looking after her two young children:

'Every human body knows what is good for them and what is bad for you if you listen to yourself...

S.P.: Do you worry about your health?

No.

S.P.: Why not?

Why not?

INT.: She doesn't concern much about the little health like common sickness like flus and [unclear] and all that. She don't have much time to pay much attention on those things because of the young family but otherwise she is a very healthy person she doesn't care about these little sicknesses...' [Pakistani woman age 30, 0501]

The account above shows how gender role obligations may affect women's own health concerns and health actions as well as their perceptions of health and symptoms of ill health.

The importance of health is linked to other factors, such as paid work or children. The accounts show that the relevance of ill health is weighed up against these other factors. These findings support other work on South Asian women (Donovan, 1986) and on white women (Popay, 1992). Popay (1992) argues that the meanings attached to the experience of ill health tell us about the reality of women's daily lives. The case above shows that women need to be healthy for themselves and differentiate between health problems so that they are able to fulfil their roles and tasks within and outwith the family.

The woman quoted below also describes her reasons for wanting to be healthy. Above I have shown that having time and space to oneself is identified by the women as a way to keep healthy. In the interview this woman feels that her individual worries are related to the constraints on her time and personal space posed by gender role obligations. She blames herself for not taking enough care of herself and is worried about her health:

'...if you don't keep yourself healthy obviously you just rot away really. That's the way I see it. I do try but obviously not hard enough sometimes...' [Pakistani woman age 23, 1301]

Some women feel that their worries about their own health and the need to be healthy change according to lifestage [5 women]. This suggests that lifestage affects how women perceive and act upon their health. For some the importance of their health and healthcare seems to ebb away later in life. The data indicate that women keep healthy to fulfil their gender role obligations, when their maternal role changes, for example as their children grow up, the need to be healthy may be given a lower priority. I shall illustrate this point by tracing the accounts of three women each in different family circumstances. The first woman has two preschool aged children, the second has three school aged children and another has two grown up children at home and two living away:

'Once you are married and once you have small children in the house you got to be healthy.' [Pakistani woman age 30, 0501]

Another woman with school aged children feels that she would take care of herself more if she were single and had no children:

'...I think that I might not be looking after myself as well as I can you know...Probably because I think I've not really been that ambitious...in life you know. Like I've got a husband a house and kids, that's about it but nothing to look forward to. It would probably be different if I was still single [laughs].' [Pakistani woman age 33, 1402]

The other woman feels less worried about her health because her children are grown up:

‘...Why worry about health you know? I not worrying [about] anything you know. Everything I got it...I am not [do not] worry, [my] children [are] OK they are all independent now you know...’ [Indian woman age 59, 1504]

Associated with the effects of gender role obligations on women’s attitudes to their own health and healthcare are deferential attitudes towards health. Eight women feel that they place more emphasis on the health of others than on their own health. This is also seen in other studies focusing on white women (Roberts, 1985). Deference mediates women’s healthcare actions. This woman illustrates how deference affects women’s attitudes to health:

‘INT.: I never save myself, looking after myself, always I got the children, so I have to look after the children, so I don’t care about myself. I never think about my body...just going on [with] things.’ [Bangladeshi woman age 27, 2701]

Deference also affects women’s attitudes to ill health as another woman shows:

‘...I worry more for the family than myself like, I don’t know why. If my sons have got the flu I’d give them Lucozade and soup and this and that, go up and down until they are all right you know. All my daughters they phone me ‘oh Mum the kids aren’t well, I’m not well’ I would worry about them, phone them all the time. I’m that kind of person, I do worry [about] everybody [more] than myself. My sister she laughs, she says ‘you should take care of yourself, don’t worry about them.’

S.P.: What do you feel when she says that?

I just feel it’s the kids, your kids most important thing...’ [Sikh woman age 42, 0903]

The women’s accounts of their healthcare include concerns about the effects of their health on others [6 women]. Such concerns lead three women to express feelings of guilt if their healthcare ‘interferes’ with others’ needs and the household. The evidence shows that feelings of guilt may mean that women are unable to fully concentrate on their own health needs:

‘But when I’m not well they wouldn’t, they would just make themselves something made [cook for themselves]. She [daughter-in-law] laughs and says ‘Mum you spoil them’. Because if they don’t want to eat *you feel bad*, you have to make something for them...’ [Sikh woman age 42, 0903] [own emphasis]

In addition, women’s concerns about the effects of their health on others lead two older women and another in her 20s to feel that they need to maintain their health to ensure their independence, so that they do not burden or depend on others:

'If my health is no good I depend on other people. I don't think they can help me anything at all because they're [her family] busy with their own things.' [Indian woman age 51, 0404]

Healthcare actions

Gender role obligations also affect the way women cope with ill health. This woman's account shows that family life shifts her attention away from her experience of symptoms of ill health. She and another woman feel that the disruption caused to a household when they are ill means that women 'are not allowed to be ill' because of the effects of their ill health on their families:

'...When I fall ill I need to be looked after as well, they don't realise that.

S.P.: Who doesn't?

The kids and him [husband] you know, they don't sort of realise...When a child falls ill you are all over them aren't you because being a mother, but they think mothers aren't allowed to be ill.

The woman is running the house and they think mother's falling ill, everything else is falling apart, things can't run to a routine. My oldest daughter is 12 she helps around the house...she sort of grew up a bit too early...It's a shame but I needed somebody there...When you're ill the kids don't understand that you need peace and quiet.' [Sikh woman age 31, 0602]

Interviews with five women show how gender role obligations affect both their recovery from ill health and patterns of healthcare in response to ill health. Popay's (1992) study on majority ethnic women's experience of ill health discusses the idea that women's social roles give them more freedom to limit their activities and to be more flexible to their needs when they are feeling ill. She challenges the use of such ideas to explain higher recorded rates of ill health among women compared to men. Such a simplistic explanation for women's health experience is also challenged in the accounts of the South Asian women here. Commonly time and flexibility are not available to women given the multiple roles that they occupy.

In terms of health maintenance, the evidence suggests that healthcare actions are also structured by the social roles women occupy. My study is unable to comment on how women in different social roles may behave differently in relation to health and ill health (Popay, 1992), however, it is able to pick out some key aspects.

Nine women show how gender role obligations affect their opportunities for health maintenance. Some recount past strategies of health maintenance, for example, 'before the children arrived.' This woman describes her methods of maintaining her health in relation to her family. She remembers what she used to do to take care of her health:

'I've not been [swimming or to the sauna] since my son's been married and everybody is invited for dinner, you don't get chance, or you're doing something is like their first Diwali [Hindu festival of light] or...inviting everybody celebrating everything, Christmas, New Year. So I've not got the time, I must start again.' [Sikh woman age 42, 0903]

This woman also links her opportunities for health maintenance to the social roles she occupies including her position in the family and in paid work. She blames herself for her 'laziness' and for not taking more care of her health and her weight:

'...there's more important things to do apart from thinking about my health. The day to day things, because I think as far as I'm concerned it's the women in our families that look after the house, they're the ones that actually run the house and keep everything going smoothly...Probably when you get to the end of the day and you've been working you think 'God can't be bothered now' I think it's getting to the point when you have done it all and I think 'this is my time now', it shouldn't be, I should be out doing something, I should be out doing it. My husband is the one actually saying to me go out and do it, like swimming or something.' [Indian woman age 33, 2002]

Nine women feel that they do not have enough time to devote to their own healthcare given the social roles they occupy. Four of these women and five others feel that gender role obligations increase the importance of social support in taking over some of these roles enabling women's opportunities for healthcare. Though, as noted above, the roles and routines of others restrict the social support that women feel they might otherwise receive [4 women].

Some feel that having more time and space for themselves would contribute to their health and well-being. This woman is typical of three others who feel that their routines revolve around their children and that this might affect her well-being and her patterns of healthcare:

'Not being able to have time for myself to do what I want to do, you know like get myself back into shape really as well.

S.P.: Not having time for yourself can you tell me a bit more?

I have got a bit more time to myself now, just recently. Like before I only had the one daughter who is at nursery and that is only one day a week. Whereas he's [son] doing three days a week so I do get more time. But I always seem to find I have so many other things to do like you know my time is gone'

‘Because at the moment it’s like what I do, everything is done around the kids, sleeping, feeding, everything. It has to be done around them so you don’t get time to sort of like do whatever you want at one time. It has to be around the children’s time when they’re away asleep or so and so.’ [Pakistani woman age 23, 1301]

From these aspects of the data I conclude that the social roles that women occupy affect their attitudes to their health, ideas about the importance of health, worries about health and healthcare and their actions to maintain health as well as their patterns of coping with ill health. Paradoxically the women feel they need to keep healthy for their children and to fulfil gender role obligations, however, some feel that they do not have time to spare. Also when their children have grown up and they have more time, they may lack the motive to keep themselves healthy. The data show that ideas about gender difference affect women’s patterns of healthcare outside health services. These findings are not easily seen in conceptualisations of access which focus on uptake and distance to health services.

The evidence shows that ‘race’ difference is also integral to women’s healthcare perspectives and experiences in this arena. This is the subject of the next section.

3.6.2 ‘Race’ dimensions of access to healthcare outside services

The effects of racism on the health experience of minority groups remain under-investigated. An access focus is relevant to help understand women’s experiences of, and perspectives on, the effects of racism on access to healthcare in all the chosen healthcare arenas. My study indicates the significance of racism in women’s access to this arena of healthcare in a number of ways outlined below. This section examines the effects of racism on women’s life chances, their perceptions of their own health and their patterns of healthcare outside health services. The findings support Fenton’s (1987: 2) idea that ‘racism is a very unhealthy thing’.

The theme of racism arose as a hazard to health and well-being. The women’s accounts of healthcare including issues about racism give rise to a broad number of issues in a number of areas of life. My study provides some evidence to show that racism influences women’s health in addition to other environmental factors such as housing. Racism affects women’s life chances and states of health. These effects are difficult to discern.

Eleven women’s accounts include the effects of racism on life chances in a number of areas such as: employment [5 women], housing [2 women], police response [2 women], their own

experience at school [5 women] or their children's experiences [3 women]. In addition, they include ideas about the effects of racism on health and well-being, in particular, on psychological health and loneliness. The women's concerns centre on safety in the outside environment [3 women], in the home [1 woman], levels of worry linked to violence against people and property [2 women] and patterns of physical restriction [2 women] in the use of space outside the home. This woman shows how racism leads to a loss of self worth and value:

'It makes you feel that you just don't belong here, and we are talking different, we are not valid...nothing your culture, your language your everything.' [Pakistani woman age 33, 0302]

From talking to women and from my own experience, racism is probably a more important factor influencing women's health than perhaps they cared to talk about. It was unsurprisingly a sensitive subject of discussion and it aroused feelings of both anger and fear. Most women recognised racism as an issue.

Racism is a part of life to which many of the women interviewed are accustomed but which is out of the control of the individual. When talking about racism the women refer to their own experiences and some refer to their families' experiences. Their accounts cover a range of environments in which women have experienced racism: on the street [11 women], on public transport [4 women], in work environments [2 women] or in neighbourhoods [3 women]. Two women perceive racism to be worse in particular areas of Edinburgh. Others refer to media coverage during the interview period, focusing on episodes of racial violence in England, changes in the law making racial violence a crime, 'race' politics and organised racism. Two women feel that the latter is increasing in Scotland. This woman links her comments to a broader analysis of racism as an everyday experience in a number of areas of life. In the interview she went on to argue that racism shapes South Asian women's experience of health services:

'Whatever it is we do we face racism in our day to day life and everywhere right from walking up the road, getting buses, children to school, dealing with neighbours you are treated differently...' [Sikh woman age 37, 0202]

The following cases illustrate the variety of experiences of racism. Three women feel lucky that they have experienced little or no racism. This woman has not experienced racism as a big issue:

'...We've not really had any problem apart from those two little incidents [name calling] I mean anybody can say that [name calling e.g. 'Paki'] and just walk away.' [Sikh woman age 30 1101]

The second woman recounts specific episodes of racism. In the interview she starts off by saying she has not experienced racism but then goes on to reveal her experience of interpersonal racism on the street and how this has affected her housing choices and so conditioned her lifechances:

'...I was working in S. once, twice for six weeks. And they are very racist in that area. We actually were offered a house up there but we refused to take it so we came up here. Walking down the street you don't feel very safe at all...All my life I have never been the victim of racism, it's really frightening...but then again if it's a young boy calling you a black so and so it really hurt. You see the horrible parts of Scotland...that I've never seen existed before...but it [racism] might just grow I don't know...when you're standing at a bus stop and somebody shouts at you.' [Sikh woman age 31, 0602]

Other women have found themselves as victims of harassment in their home environments. The woman quoted below recounts prolonged interpersonal racism as an everyday experience. This not only affects her lifechances but also directly affects her psychological health. She describes her experience of racism as a kind of 'hell'. In the interview she refers to herself as 'an outcast' in the UK:

'...the Council allotted us a house and two and a half year hell. All the windows were boarded and we were boarded outside because every time we near them the kids come with balls and threw it. And one day my two daughters they were in the bedroom...and they smashed the window and big brick and the glass and the window came...and they smash the car and they say 'you will be finished and will do that' and they keep writing on the door, my goodness it was a dirty word.' [Pakistani woman age 48, 1803]

The woman quoted below links racism to her well-being, feelings about the need to be healthy and to her healthcare actions. Her account also illustrates overlaps between ideas about 'race' and gender difference in South Asian women's healthcare experiences. In common with the last section on ideas about gender difference and access to healthcare this woman links her health and her own healthcare practices to the well-being of others:

'S.P.: Do you worry about your health?

Sometimes about you know after the baby is born I am worried because I am living alone here and I want to be healthy and you know, and you know is I want to do everything myself but I can't because I am very weak...getting food you know is getting vegetables. Sometimes force myself to eat meat as well because I want to [keep healthy] you know is my kids I can't go through like that.

S.P.: You said you are worried because you are alone here?

Yes. And my husband is going to work he can't spend all the day at home so I am worried who look after my children so that's why, I want to be healthy.' [Pakistani woman age 27, 3101]

This woman links her need to be healthy to a much broader analysis arguing that racism shapes her healthcare actions. She feels that she has to work harder and it is more difficult for her to maintain her health and to be healthy compared to other women. She feels that racism shapes her health experience and extends this to the experience of other South Asian people. She describes her experience of exclusion in her home space in the close in which she lives:

'They hate our children, that's it...If I want to go...in Edinburgh [city centre] you know is far away and in every area I can go myself in the bus and I take my children as well. If I don't be [am not] healthy I can't do this, so health is very important, especially for us. Health is better and good for everyone but I feel health is most important for us because we are alone here and we do everything by self and don't have anybody to help us. That's why...our people and our Asian women feel alone and don't like them. Mostly Asian people don't like these peoples this is the reason because they don't like us.

In Manchester in London...not these problems they have big families there you know is big, Asian people's shop and they don't bother them but we have to bother because we are alone and small community that's why.' [Pakistani woman age 27, 3101]

Racism affects some women's attitudes to health. This woman feels that her health is important for a number of reasons. Firstly, because she feels alone. Secondly, she links her health to gender role obligations and argues that her health is also important for her children as it impacts on her ability to care for them. Thirdly, she links the exclusion that she feels to her need to be healthy and to her healthcare actions.

Writers argue that racism is the basis of minority ethnic women's experiences in the UK (Douglas, 1992; Donovan, 1986). Chapter 1 argued that the literature on minority ethnic groups and healthcare pays more attention to the effects of racism on healthcare inside than outside services. The findings here suggest that racism has wider implications for healthcare more generally. The data suggest that racism affects women's health, well-being, life chances, individual perceptions of health and individual health actions outside services. This supports my conceptualisation of healthcare as more than just the use of health services. The findings support those of Donovan (1986) who found that racism is closely related to both health and ill health. Her study on South Asian women and Afro-Caribbean men and women found most respondents believed racism to be relevant to their health experience. They also support other authors (Howlett *et al.*, 1992; Cox and Bostock, 1989;

Fenton, 1987; Rathwell and Phillips, 1986) who argue that racism is a significant cause of ill health in the UK.

Women's experiences of racism were talked about in the context of their ideas about health and healthcare. The rest of this section examines women's responses to racism. It provides further insight into women's experiences of racism and its effects on health, well-being and life chances. Further examination of women's discussions of racism is given in the next chapter (section 4.6.3).

The findings show that not only do women vary in their experiences of racism but also in their responses to racism. Some women's responses were more philosophical than others:

'It's I'm not saying there's no racism here, there's no prejudice there...It's always there. It will always be there. It doesn't matter how illegal they make it, it's always going to be there...I always think there is a hidden racism as well...They could be nice to your face but at the back they hate your guts because you're black. I think that's the most dangerous part of racism as well. It's very difficult to find out you can't tell if it's there. It's like stabbing someone behind the back... [Indian woman age 33, 1602]

This woman is less 'resigned' to the experience:

'At this time and place this is our home we have to work for it and do what we can. We are not 'taking it off' [welfare resources and jobs] anybody else. We have got the education, we've got everything, we are doing it ourselves we are not going to ask from anyone. We are just going to stand up and make it you know, it doesn't matter what anybody says...So I wouldn't take it [racist abuse] from anyone- oh 'you're here' and 'you're taking our jobs' and things like that...Some say we can't handle this, and don't say nothing just forget it, let them use and abuse you but not this time.' [Sikh woman age 30, 1101]

The women make sense of their experiences of racism in a number of ways. This is linked to the number of South Asian women and the mix of ethnic groups in particular places. The interview data suggest that women's attitudes to racism are tied to their life experiences and are formed in particular places. Some women make comparisons between Edinburgh and mainly urban areas 'down South', that is England. Population numbers are perceived to have some bearing on the experience of racism. Eight women feel that more South Asian people in an area may be associated with resentment and racism. It is paradoxical that for three women a larger South Asian community might cushion against racism, increasing a sense of safety and providing support should incidents occur.

'...In England there is such a large population of ethnic minorities...maybe that's why people...I feel it is different in a sense because it's such a larger community [of minority

ethnic groups] there [in England] that people accept more, accept more different people but at the same time there is also the problem that there is too many...there is also the conflict and the problems there as well.' [Pakistani woman age 33, 0302]

'there's more Asians in Glasgow and there's even more in England so I feel that there is sort of...there's resentment there...' [Sikh woman age 44, 0703]

'...You do hear a lot about it happening in England and so on, but not much in Scotland...Maybe there is not many Asian families here I don't know. Well I think it depends on how you mix with people as well. If you keep yourself to yourself more 'oh I am Asian I am not going to mix with Scottish people' I think it will come upon you, you know...' [Sikh woman age 30, 1101]

The theme of mixing is also seen in women's accounts of racism. Four women perceive the situation to be different in Scotland, as 'down South' there are more minority ethnic groups than in Edinburgh and that the mixing of ethnic groups may lead to more tolerance and to less racism. In addition, nine women feel that being seen to 'stand out', either as a group or as an individual, leads to a greater experience of racism, and that this may be avoided if one is seen to 'mix in.' The quotations indicate how women try to take control of the experiences of racism:

'...I think it's more easier if you can sort of mix in a bit more for yourself, especially where the racism is concerned...' [Sikh woman age 31, 0602]

'You compromise, get on with the [wider] community...try to mix...not make yourself stand out against them, like we are different. Know what I mean?' [Pakistani woman age 33, 1402]

'Sometimes when I am treated differently it's not me who feels that I am different, people make me feel that I am different. So that hurts little bit. Yes it does sometimes hurt because people make you feel that you are different...they make it a point to make you realise that you are different...When they say integrating, even people do try to integrate but nobody will let you integrate. [Sikh woman age 37, 0202]

The final quotation shows that mixing in is not always possible and that the response of the wider society toward minority ethnic groups is as important as minority ethnic groups' ability to mix in.

The accounts show that racism takes a number forms. When discussing interpersonal racism experienced on the streets for example, eight women's accounts reflect the processes of stereotyping and labelling where South Asians are constructed as a distinct category called 'Paki' (Brah, 1992). This is recounted in this woman's experience of abuse:

'...they didn't take India, Bangladesh, Asia, China, Korea they don't think. They all say they are all Paki...They thinks all the same.' [Indian woman age 32, 2202]

Other forms of racism also arise in the accounts. Fourteen women's accounts include racist metaphors to describe their perceptions and experiences of racism. In the main these reflect on and question the presence and rights of minority ethnic groups in the UK. They include ideas like 'they don't belong here', 'this is not your country' or there are 'too many Asians'.

Women's perceptions of and experiences of racism and their effects on health and patterns of healthcare are difficult to discern. This section has highlighted the complexity and dynamism of racism as a phenomenon. It occurs in a variety of ways and in a number of different contexts. I have shown that women's attitudes to racism are formed in particular places as well as through their life experiences and that racism affects women in different ways. The effects of racism on access to healthcare are therefore not monolithic or deterministic. The evidence shows that racism affects women's health and well-being and affects patterns of healthcare outside health services. Chapter 4 devotes more attention to the ways in which women discuss racism and the effects of racism on South Asian women's access to other healthcare arenas, in particular, health services.

3.7 Conclusion

This chapter has investigated South Asian women's access to healthcare outside services, my first chosen healthcare arena. My findings challenge the results of previous research and provide evidence to dispute many commonly held stereotypes of South Asian women's health beliefs and behaviours including women's orientation to their health, the construction and particularization of minority ethnic groups' health problems, stereotypes of South Asian women's strategies to manage ill health and the emphasis on differences between South Asian women's and other women's health behaviours.

On women's orientations to their health, health is important to those interviewed. They possess strong ideas about their health and healthcare and are keen to improve their health. Chapter 1 showed that South Asian women's health behaviours may be pathologised. As a consequence health policy responses have centred on the health education of South Asian women in an attempt to get them to adopt a more 'British' way of life. My findings challenge the view that minority ethnic groups are a danger to their own health and so open up the possibility of developing less ethnocentric and more effective health policies.

The interview data have shown that South Asian women's own views about healthcare often differ from those pinpointed by cultural stereotyping or by much previous research as shown

in chapter 1. These findings challenge both the construction and the particularization of minority ethnic groups' health problems. They have shown that the women's own health concerns do not reflect the exoticised health issues prioritised in the literature on minority ethnic groups and health, nor the health problems targeted in health policy aimed at minority ethnic groups. The women's own assessments of health show that they are more concerned about health problems such as asthma, diabetes, weight, changes in health state, menopause, hereditary health problems and mental ill-being, than issues such as *surma* poisoning, tuberculosis and rickets. In conclusion, the health issues identified by South Asian women are much broader than those marked in the literature on minority ethnic groups and healthcare.

Further, my findings on the management of healthcare have also challenged stereotypes of South Asian women's health behaviours. For example, the interview data have emphasised the importance of social support in the women's healthcare. However, they have shown that women's use of social support does not necessarily tie in with stereotypical assumptions about non-professional help and support available to South Asian women. The stereotypical family support network did not necessarily exist or operate, and even when it did, it was not necessarily the preferred pathway of care for many of the women interviewed. I have shown, nonetheless, that social support plays a number of roles in South Asian women's healthcare, providing educational, practical and psychological support. And I have suggested that women's use of social support is associated with constraints on access to health services.

The interview data on women's management of health and ill health have also shown that healthcare does not occupy a separate sphere of life and that healthcare is negotiated from a number of different sources. It is difficult to separate women's health attitudes and actions from what is going on in the rest of their lives. Their own health, for example, is considered in the context of other people's needs, women's social responsibilities and social roles and in the context of life events such as migration and lifestage.

On the emphasis on differences between minority ethnic women's and majority ethnic women's health behaviours, it is clear from the data on women's management of health that, when judged against published work on gender and health, the similarities in South Asian women's health attitudes and actions are stronger than the differences between them and majority ethnic women. Like other women, the South Asian women interviewed are part of

an unpaid healthcare force and play a central role in family health. Often this occurs to the detriment of their own healthcare needs. The obligations attached to gender roles affect women's attitudes to their health, ideas about the importance of health, worries about health and healthcare, their actions to maintain health and patterns of coping with ill health. These findings are important because they challenge a literature that has emphasised the distinct health attitudes and actions of minority ethnic groups compared to the majority ethnic group. They challenge a view that differences in access to healthcare between minority ethnic groups and majority ethnic groups reflect cultural norms or preferences. They also challenge the devaluation of women's healthcare practices that do not involve formal health service use.

My study has shown that where differences between South Asian women's and majority ethnic women's healthcare attitudes and practices do arise, these relate to the experience of racism. I have provided some exploratory evidence which suggests that racism affects women's health and well-being, especially psychological health, women's life chances and mobility. Racism may also affect women's healthcare actions such as the use of social support. These findings are important as previous understandings of the effects of racism on minority ethnic groups' healthcare have tended to focus on access to health services. To some extent this tendency has curtailed understandings of the effects of racism on access to healthcare in its broadest sense. My study supports the need to extend ideas about the effects of racism on South Asian women's access to healthcare to other healthcare arenas. In addition, the findings are important as they suggest that the effects of racism on access to healthcare should not be divorced from the experience of racism in other areas of life.

Finally, this chapter has shown that healthcare outside services and formal healthcare provision do not exist independently of each other. For example, my findings have shown that health visitors play a positive role in women's healthcare in this arena, women's use of medicines is influenced by their health service experience and that social support is used in response to women's perceptions and experiences of health services. The next chapter examines access to the GP service, which is often the usual gateway into the formal health service arena.

Access to the GP service and South Asian Women

4.1 Introduction

Chapter 3 showed that South Asian women negotiate healthcare from a number of different sources and examined women's experiences and perceptions of healthcare that do not involve formal service use. My focus now shifts inside health services. This chapter explores South Asian women's access to the GP service, my second chosen healthcare arena. This is important because the GP is part of mainstream healthcare provision and is a gateway to other health services and welfare resources. For example, the recent drive towards healthcare restructuring has emphasised the role of the GP in preventative healthcare provision, including cervical cytology which is considered in chapter 5.

The sections describe women's pathways into the GP system, their attitudes to GPs, how they decide to use the GP service and the role of the GP service in their healthcare. Three central themes in the women's GP experiences and the negotiation of GP care are then examined: the organisation of the GP system, women's attitudes toward prescribed medicines and their attitudes toward information and explanation gained from the GP. The analysis describes both individual and collective factors affecting access to the GP service. The final sections examine ideas about 'race' and gender difference and their effects on South Asian women's access to the service. I argue that the patterns of access to, and use of, GP care for South Asian women are a response not so much to South Asian culture as conventionally understood, but to the structure and the attributes of the GP service.

4.2 Background: South Asian women and access to the GP service

Little is written about what South Asian GP users think about their interactions with GPs. Notable exceptions are Bowes and Domokos (1995c), Ahmad *et al.* (1991a, 1991b, 1989b), Fenton and Poonia (1988) and Wright (1983). This reflects a sparse literature on minority ethnic groups' access to health and health services from the point of view of the service

user. Like access to healthcare outside services, I would argue that understandings of access to the GP service must be informed by the perspectives and experiences of minority ethnic groups, in this case South Asian women.

In the UK the GP is a mainstream health service entitlement where universal access is assumed for all. The GP is used episodically for a variety of healthcare reasons, and the majority of decisions to consult are taken by the GP user. There are no restrictions on the type of problem patients can refer to a GP. This contrasts with cervical cytology, for example, where service use is more specific and the frequency of uptake is defined by health policy. As noted above, the GP is a gateway to care, controlling not only access to their own time, expertise and attention but also access to a range of healthcare resources and other sources of care (Foster, 1983). Like access to healthcare outside services, explanations for South Asian groups' patterns of GP use have centred around ideas about South Asian culture. This has meant that the 'race' and gender dimensions of access have become submerged and that explanations of access to the service have centred on the attributes of South Asian GP users rather than on the attributes and structure of the GP service or on South Asian GP users' experiences of, and perspectives on, the GP.

In this chapter, different dimensions of the cultural approach are explored. In particular, it addresses the pathologisation of: South Asian women's patterns of GP use and the nature of their GP consultations. Studies show that GPs perceive that South Asian GP users consult 'too much' (Ahmad *et al.*, 1991b; Fenton, 1987; Wright, 1983) and make inappropriate use of health services, often with more trivial complaints or ill-defined conditions when compared to non-Asian patients (Ahmad *et al.*, 1991b; Wright, 1983). They also show that GPs perceive South Asians require longer consultations, are less compliant and that consultations with South Asians are less satisfying than those with non-Asian users (Ahmad *et al.*, 1991b; Wright, 1983). In Wright's (1989) study no GP felt that Asians took up less time or consulted less often than non-Asians. The implication is that South Asians as a group are a burden on services (Johnson *et al.*, 1983).

These authors put forward a range of explanations for their findings. Ahmad *et al.* (1991b) suggest that the social distance between South Asian GP users and GPs shapes the negative attitudes which the GPs displayed. Wright (1983) explains her findings by emphasising a gap of culture and communication between GPs and South Asian GP users. She also identifies the unwillingness of GPs to change in response to the changing population.

Finally, Fenton (1987) argues that GPs tend to underestimate the problems facing minority ethnic users.

A number of authors have debated GP uptake rates by minority ethnic groups (e.g. Heatley and Yip, 1991; Wright, 1983). Whilst rates of use are not the focus of my study, it complements others that have used quantitative methods to debate ideas about the use and overuse of the GP by minority ethnic groups (Pilgrim *et al.*, 1993; Ebrahim *et al.*, 1991; Heatley and Yip, 1991; McCormick and Rosenbaum, 1990; Gillam *et al.*, 1989; Balajaran *et al.*, 1989; Fenton, 1987; Blakemore, 1983; Johnson *et al.*, 1983). Pilgrim *et al.* (1993), Johnson *et al.* (1983) and Heatley and Yip (1991) found no significant differences in consultation rates between the minority ethnic groups they interviewed and the majority ethnic population, whilst HEA (1994), McCormick and Rosenbaum (1990), Balajaran *et al.* (1989) and Gillam *et al.*, (1989) found higher consultation rates among the South Asian population compared to national figures. The picture of GP use remains unclear. Some studies have highlighted differences in consultation rates by age. Ebrahim *et al.* (1991), and Pilgrim *et al.* (1993) found higher rates of utilisation among white elders compared to minority ethnic elders. Some have found differences by gender. Balajaran *et al.* (1989) and Gillam *et al.* (1989) found higher rates of use by minority ethnic men than women. Other studies have also found differences in GP use according to South Asian category (e.g. HEA, 1994; Balajaran *et al.*, 1989). Most of these studies however, do not control for morbidity which affects service uptake.

Doubts, therefore, remain over explanations for GP use among South Asians (Gillam *et al.*, 1989). It is difficult to pinpoint why differences in the patterns of nature and use might occur. One of the main reasons for this is that so far explanations of GP use have failed to take into account the experiences and perspectives of minority ethnic groups themselves and have failed to use them to inform the concept of access. Explanations of under and over-utilisation relative to need may indicate poorer services, a lack of information or appropriate care, or may indicate high morbidity. The latter is indicated in: Ebrahim *et al.*'s (1991) study of chronic conditions among Gujarati elders; and in Johnson *et al.*'s (1983) study which stressed that minority ethnic groups often live in inner city areas with poor housing, overcrowding and unemployment, and that all of these factors are known to lead to a higher incidence of ill health.

A broader view of access will help us to understand women's perspectives and experiences. It urges a move beyond some of the medical literature on GPs and minority ethnic groups which has used 'race' as an independent variable to measure consultation rates. My study adds to the small amount of research that examines: how South Asian women access GPs, the constraints and enablements on their access to the service, and women's views and feelings about their interaction with GPs.

4.3 Women's attitudes to the GP - key issues and concerns

All 36 women talk about their current GPs, many also draw on their past GP experiences. Some refer to their family's or friends' experiences, especially those of other South Asian women. Others extend their own experiences to other South Asian women. Section 4.3.2 considers the range of women's attitudes toward GPs. First I shall outline women's pathways to their current GPs, as this informs their attitudes to GPs more generally.

4.3.1 Women's pathways to the GP system

All the women interviewed are registered with a GP. Such high rates of registration support Smith's (1991) study in Scotland which showed that minority ethnic respondents are just as likely to be registered with GPs as white respondents, and the HEA (1994) English based study which showed that only small proportions of minority ethnic groups are not registered with a GP. Table 4.1 shows that most women are registered with group practices that include other primary care workers. Some women consider a GP other than the GP they are registered with to be their GP. In such cases, my questioning refers to the GP that is considered to be their own. Two women do not know exactly which GP they are registered with. All the women have seen a GP within the last year.

GP/Practice characteristic	No. women in each ethnic category				
	B/deshi	Pakistani	Indian	Sikh	Total
Reg. with Female GP	5	4	3	3	15
Reg. with Male GP	4	5	4	6	19
Asian lang. speaking GP	0	0	1	1	2
Group practice	9	9	8	7	33
Single practice	0	0	1	2	3
Nearest practice	8	6	5	6	25
At practice since lived in the area	5	4	7	2	18

Table 4.1 The women's GPs

Table 4.2 suggests that choice is important to the women when registering with a GP. Most women identify more than one factor when describing their pathways to the GP service.

Pathway	No. women
Near to home	13
Influenced by sources of social support	
- other than family	13
- family	10
- husband/partner	7
Chose self (no specific reason voiced)	6
Seen GP before and decide to register	6
Chose after changing GP registered with	6
Allocated by health prof. e.g. after GP retired	4
Has many Asian patients	4
Wants surgery with health visitor	2
Advised by past GP when moving	1
Seek out Asian GP	1
Knew GP before-previously lived in area	1

Table 4.2 Pathways to the GP: Reasons for registering with the GP

Physical distance from the service affects women's pathways to the GP [13 women], however, women's concerns about physical distance are meshed with other dimensions of access to care. This woman's concerns about distance to the GP are tied to her gender role obligations:

'...Because it [surgery] was far, like if my kids wanted to go I had to have the car to take them up. Sometimes I never used to have the car and it was really far. But calling the doctor [out] for just a wee thing is really bad if it's not like that worse [bad].' [Sikh woman age 38, 1002]

Social support provides information to enable access to the service. Sixteen women remember that this was particularly important for them as they were new to the area when they registered with their GPs. Good reports about GPs seem to be more important than ideas about the services the GP surgery offers. Thirteen women identify the importance of input from others such as neighbours and friends, especially other South Asian women, to enable choice and to allay any concerns they have when registering with their GP.

'...I heard that he was very good from my friend, he's very sympathetic...It wasn't just my friend he has been my parents' doctor for a long time...I just felt that because I had heard some good reports, like I say he was sympathetic and easy to call out if it was needed then, and plus the fact that he has all the records for the rest of the family I thought it was easier and perhaps better in the long run.' [Indian woman age 33, 1702]

The ethnic background of other GP users is also important when registering. Two women feel reassured in their decision to register because their GPs have other South Asian patients:

‘But my doctor is I don't know quite nice, she is very nice. I don't know other doctor. My doctor has got so many Pakistani [patients] they say she is very good no? She got so many Pakistani patient

S.P.: Did that affect how you chose your doctor?

Yes because same area near you know.’ [Indian woman age 59, 1504]

The following sections consider women's attitudes toward GPs. They expand on the women's ideas about choice and access to GP care.

4.3.2 The range of women's attitudes toward GPs

Little is known about patients' feelings about, and relationships with, their GPs (Roberts, 1985). The interview data show that women's attitudes toward GPs vary and are shaped by a number of factors, in particular, ‘previous health service interactions and their experiences as patients’ (Blaxter and Paterson 1982: 156). In sections 4.3.3-4.3.5 I elaborate on three themes which arise in the women's accounts, firstly, positive and negative relationships with GPs, secondly, the interchangeability of GPs, and thirdly, women's GP preferences. I will argue that women's attitudes toward GPs intervene between their health attitudes and the use of the GP service, though they do not determine help seeking behaviour more generally.

The accounts include ideas about the authority of doctors:

‘I am not a doctor she [GP] know everything’ [Bangladeshi woman age 41, 3203]

‘...you can trust the doctor, because you know the doctor is telling you the right thing to do and you know you'll be better.

S.P.: And your sons and your family?

You listen to them but you still think the doctor's right.’ [Sikh woman age 38, 1002]

‘...We don't know, I mean I don't know anything, we have to trust them...They all been through this professional degrees, education, they know what they are talking about.’ [Indian woman age 33, 1602]

'S.P.: Can you tell me about the relationship between you and your doctor?

...They are very friendly and I respect them because they are educated people, they know so much about it.' [Bangladeshi woman age 31, 2402]

According to Roberts (1985) the consultation is a social and medical encounter in which doctors have the power to define what is ill health and health and what goes on in the consultation. The context of care is one of medical expertise and medical power, and the relationship between GP users and GPs is unequal (Cornwell, 1984). Where experts bestow and users receive care these dimensions of power may be hidden (Roberts, 1985).

The women's conceptions of the authority of doctors come from the idea that GPs possess particular kinds of skills and knowledge. Cornwell's (1984) study on the experience of health and ill health among majority ethnic families in East London, shows that these types of attitudes are based on the assumption: that GPs are trained, know things that others do not and that medicine is a science. Similarly, my study suggests that South Asian women's attitudes to GPs are affected by a conception of professionalism which focuses on the expertise of the GP.

This type of medical expertise is not, in the end, the skill that women value in actual consultations and in their ongoing relationships with GPs. The women's attitudes toward GPs centre not so much on medical criteria (medical skills or qualifications) but on the social skills of the GP. That is to say the women make sense of their actual experience of the GP and their judgements and ideals about good practice, in terms of the social skills rather than the medical expertise of the GP. They place less emphasis on diagnosis, examinations or prescriptions and more on social aspects of communication, for example, the time to talk, the ability to listen to the user, and the GPs' willingness to spend time with them (see table 4.3). This theme is significant as many women voice their concerns about social aspects of the consultation. Some illustrate how social aspects can act to constrain women's access to the GP (see below).

4.3.3 Positive and negative relationships with GPs

The women describe aspects of the GP-patient relationship and the kind of relationship that they would like. For analytical purposes I have divided the accounts into positive and negative relationships with GPs, though in reality a continuum of relationships between women and their GPs exists. The accounts show that a number of factors shape women's

relationships with GPs. Firstly, women's views about GPs are based on past and present experiences and ideals about GPs. Secondly, the women's attitudes toward GPs are voiced through the experiences of their families, in particular their children. In common with other studies (Cornwell, 1984), the women's actual experience of the GP may not fit with their idealised expectations of the GP-patient relationship and that some feel they ought to have better relationships with GPs.

It is possible to distinguish between women's own GP experiences and their perceptions about what constitutes a relatively 'good' and 'bad' GP relationship. Table 4.3 summarises the women's main ideas about relationships with GPs. The table was compiled after carrying out the interviews, transcribing, repeated reading and preliminary analysis of the findings. The themes are discussed below and are supported with quotations.

	Positive relationship with GP	Negative relationship with GP	Experience	Perception	Experience	Perception
	Factor	Factor				
More social skills	Listens	Not listen	12	10	8	2
	Feels able to talk to		13	2		
	Feels has time	Feels rushed	7	2	6	3
	Explains health problem	Does not explain health problem	8	4	5	2
		No info. in own language			1	0
	Feel able to discuss problem	Unable to discuss	4	4	3	1
	Takes seriously/sympathetic	Feels GP does not take seriously	3	2	8	4
	Understanding	Feels GP is angry	4	2	4	1
	Reassuring/supportive	Feels GP is not reassuring	6	2	0	1
	Friendly		10	3		
	GPs are nice people		7	1		
	Cares about users	Feels GP does not care	2	1	0	1
	Knows persons health history	Not know health history	7	1	1	0
	Knows/asks about life history	Feel GP does not know user	8	3	1	2
	Makes general conversation		6	1		
	Is helpful		4	1		
More medical skills	Examines thoroughly		4	0		
	Gives medicine		8	6		
		Feels GP does not examine thoroughly			5	1
		Feels GP does not give medicine			3	2
		Prescribes without thorough examination			4	4
		Feel GP not prescribe if can buy over the counter			3	0
		Not come if called out			5	5
		Not allow for language problems			4	1
Language	Feels able to call out		9	1		
	Understand/allow for language problems		3	0		
	Feels able to approach anytime		5	1		
	Feels able to approach for mental health concerns		1	1		
Approachability	GP is concerned about mental health		2	1		
	Refers when feel it is needed	Feels not concerned about mental health	6	0	2	0
	Treated as individual	Feels not refer	2	2	2	0
	GP does not stereotype health behaviour/problem	Not treated as individual	0	1	0	1
More social skills		Feels GP stereotypes health behaviour				
		Feels GP is critical of user			0	2

Table 4.3 Factors contributing to positive and negative relationships with GPs

A close reading of the transcripts shows that most women are positive about a number of aspects of GP care and find it easier to talk about positive relationships with GPs than negative ones. Four women, however, feel that they have little relationship with their GPs.

Positive relationships with GPs

The quality of interaction and communication between GPs and users is central to women's attitudes toward, and relationships with, their GPs. These three women highlight the sorts of skill valued and emphasise the social skills of listening, understanding, reassuring and explaining:

'It's like communication, if they're nice they can hear, they listen to you and it's good to know that they understand, it's like any profession. Communication things, like they understand, they're trying to help you. They are trying to help you, they are doing their best, they are reassuring, all these things. This works wonders besides medicine doesn't it? Reassuring things... They explain to you why is this, why this should happen this way. If this goes wrong, your mind doesn't rest. They explain to you. You're not left wondering oh my God, will I live another two years or not, sort of thing. That they can explain, it does help...' [Indian woman age 33, 1602]

'...I usually do all the talking when I go and she listens, that's the main thing I feel happy about she listens. Any advice I need she's always a great help.' [Bangladeshi woman age 26, 3701]

Sympathy and responsiveness is also valued:

'...If you go down there...you explain the symptoms and they don't seem to be very sympathetic about your problem, I don't think they should be there at all. For yourself, you might think the problem is quite bad, for them it might not be that much, but they should...realise that...you make the effort to go there and see them...' [Pakistani woman age 33, 1402]

Eleven women identify the importance of the GP having personal knowledge about them and their life histories beyond the given health problem that is presented to the GP. Asking about children for instance is identified as something that puts the women at ease. Familiarity with health and life courses enables communication in the consultation. The following comments are indicative of this theme and arose when discussing relationships with GPs:

'I think a doctor should get close to you, meaning they should know what kind of person you are, I think that's important for a family doctor, because they'll know you over the years...Just how the kids are, you know what I mean, to sort of talk that's what makes a person feel at ease. And they know that you are sort of...one to one person...become a

friend as well, although they are sorting your problems out you know.’ [Sikh woman age 31, 0602]

‘...Just you know very friendly. How is it? how is your family? Just very general questions I would like to find out a little bit about you, so you can have a good relationship, so you understand. You know if they found out about your background, your life then they can deal with any problems that will be occurring in your life...then feel comfortable to say anything that you want and not try to hide the problems that you have got...’ [Pakistani woman age 33, 0302]

Communication also affects GP use:

‘...because she knows me quite well and I know her and I feel more comfortable with her. If you feel uncomfortable with someone that you can’t talk to, there’s no point in going you know.

S.P.: You know her?

Like I say I can talk to her about things, I don’t know her personal name, that’s not what I mean. I can talk to her and she does listen, you know that’s why I feel comfortable with her. But if there was another doctor maybe I’d feel a bit out of place...’ [Bangladeshi woman age 26, 3701]

This section has shown that communication, in its broadest sense, is valued in consultations. Good communication mediates inequalities in the relationship between GPs and GP users and helps to reduce the power gap between both parties. The women feel it is important that the GP listens to them, spends time with them, is friendly and has knowledge about them and their lives. They emphasise the importance of interactive consultations, where the woman is a source of advice about her body and health and she feels involved in the treatment process.

Negative relationships with GPs

In common with other studies on minority ethnic groups (Pilgrim *et al.*, 1993; Donovan, 1986) and white women (Roberts, 1985) the women find it hard to criticise GPs openly. In contrast to women’s positive comments about GPs, they often refer to particular GPs rather than GPs in general. That is not to say that the women do not talk about their negative experiences, indeed many comments arose unprompted. Rather, the women do not want to label GPs as ‘bad’. Such reluctance is bound up with women’s concerns about the pressure placed on the health system, and the ‘demise of’ the NHS. Some women draw on past negative health service experiences, and on their experience of healthcare in the Indian subcontinent to balance their concerns about negative relationships with GPs.

In parallel with ideas about positive relationships with GPs, a central theme is communication in the consultation. The evidence suggests that communication problems partly originate with the GP not with the women. The women criticise GPs who: do not listen, do not seem to take their problems seriously, make them feel rushed, do not consult the GP user before taking further steps and are more interested in the patients files than the patient themselves. They are concerned that doctors may not be hearing their voices. This evidence challenges understandings of South Asian groups and access to health services that have centred on the attributes of minority ethnic health service users, but which fail to consider the attributes of health services.

‘...very bad tempered, he never used to listen to anything. There were lots of things I wanted to discuss with him, a problem or whatever, but he made you feel so uneasy that you didn’t want to say ‘hello’ to him in case you got offended...’ [Bangladeshi woman age 26, 3701].

‘...They don't even have much time to listen to you.

S.P.: Tell me about that...

You just tell for your medical things and after that they just want to write the prescription, okay, that’s fine. You can feel the doctor say get out from here now...

Because they have others sitting there, that’s why they have no time to listen to you very much. You can understand these things...but I feel like more talking. But when he’s sitting in the surgery he has no time when other people are standing and waiting there. It is no help for the doctor or me if I keep talking...you can’t say anything, you can’t say ‘no you have to take the time for me’” [Indian woman age 51, 0404]

Communication difficulties affect access to GPs in a number of different ways. Firstly, they may act to deny women a full knowledge about their health problems that they present to the GP. Secondly, they may stop women gaining some form of control over medical decisions that affect their own well-being. In some cases this makes women reluctant to approach their GPs. This is particularly relevant with respect to mental health problems (considered below). Two women volunteer that they have changed GPs because they felt their GPs held negative attitudes toward them.

As noted above, access to the GP is compromised due to difficulties in and ineffective communication between GPs and GP users. At first glance this finding is unsurprising, for other health service users the issue of communication is paramount in the consultation (Roberts, 1985; Pendleton, 1983; Homans and Satow, 1982). However, for minority ethnic groups the medical literature in particular, has prioritised the issue of language constraints

on access to healthcare. This reflects the overlay of culture where communication problems play a major role in the negative typification of South Asian women (Bowler, 1993b). Whilst not wishing to deny it as an issue, it is damaging to prioritise language difficulties if it means that attention is shifted away from the broader issues of communication and ideas about access that are emphasised for other GP users.

Another theme in women's accounts of negative relationships with GPs is the way in which care or treatment is conveyed. Negative aspects of care identified are that GPs never examine the patient, or do not examine a patient properly. Some women are concerned about the time in the consultation and feel uneasy when the GP 'rushes you in and out', or writes a prescription 'as soon as one comes in the door'. Other women feel that GPs are unwilling to prescribe in certain circumstances, for example, if medicines can be bought over the counter (discussed further in section 4.5.2).

Two women talk more directly about their negative attitudes toward their GPs and describe how this affects their GP experiences and the uptake of care. They talk impersonally about their GPs and their concerns revolve around social aspects of the consultation. Positive aspects of communication are notably absent in their accounts and are linked to their patterns of GP use.

One woman feels that her GP does not trust her and is unsympathetic to her problems because the GP feels that there is nothing wrong with her. She feels that her GP might deny her access to the treatment that she wants. She asks others about her state of health to reinforce her decision to reconsult the GP for the same health problem.

The other woman is clearly very disgruntled with her GP and recounts instances where she felt the treatment was unsatisfactory. Her perceptions of her GP are structured by her current GP experience and her feelings about the different relations between South Asian women and health services. In the interview she feels her relationship with the GP system differs compared to other users. She feels excluded from the GP service and is sceptical about her GP's responsiveness to her needs:

'Because they don't understand our problems, they don't listen to your thinking and our pains, they says 'just take paracetamol', just you know strong tablets that's it and so if it's something problems you know seriously [serious health problems] so you go to the GP and that's it' [Pakistani woman age 27, 3101].

This affects her expectations of the GP system, and her subsequent use of the GP. She uses the GP only for serious health problems. Positive and negative ideas about GPs affect women's relationships with GPs, and this, the interview data suggest, may affect their patterns of GP use. The next section discusses another theme from the interviews, that of the interchangeability of GPs.

4.3.4 The interchangeability of GPs

Although most women feel that it is important to see the same or their own GP, many also see other GPs. Eight women feel that GPs are interchangeable. This perception affects women's patterns of GP use and their GP experience. As noted above, the women are reluctant to criticise GPs, and it is the perceived interchangeability of GPs which allows them to avoid criticism.

'...Doctors are doctors aren't they? They're all looking after everybody and they're supposed to save a life...' [Sikh woman age 42, 0903]

The perception of GP interchangeability helps the women to avoid disappointment if their GP preferences are not met. This woman wants to see a woman doctor for her particular health concerns, but comforts herself with the view that a 'doctor's a doctor' when her preference is not met:

'...They ask for them [woman doctors], but now everyone has come to the conclusion that if it's available it's available, if not, a doctor's a doctor.' [Sikh woman age 67, 1204]

The second strategy to avoid criticism of GPs is to move away from the social skills of the GP to focus on the medical skills of the GP. Some women feel that all GPs are interchangeable and that they treat GP users similarly:

'If [you have] any disease anything they [GPs] all give you the same medicine as other...' [Indian woman age 59, 1504]

Associated with women's avoidance of criticism of GPs are attitudes of gratitude and deference. This may explain why they are perhaps less critical than they might be about their experiences of GP care. All the women, are grateful for the GP care that they have received. Six women are pleased to have access to the NHS and to free healthcare and recount their past experiences outside the UK. They compare their experiences with those in the Indian subcontinent.

For one woman ideas about the interchangeability of GPs are linked to her feelings about the unequal relationships between minority ethnic groups and health services. The perception that GPs are 'all the same' allows her to express the constraints she feels in her use of the service. She feels that her sense of choice of GP compares unfavourably to other GP users:

'S.P.: So how did you come to be with this doctor?

Yes is lady doctor...

S.P.: How did you come to register there?

Yes this is nearest one.

S.P.: Is that how you chose your doctor, how did you choose your doctor?

When I moved here you know is two [Pakistani] families before, they say this is good surgery and you know is all the surgeries, two surgeries they are same, here which one you want you have to go. But they both have a lady doctor... so I choose this surgery so this is the nearest one and I have a lady doctor...*every surgery is [the] same, because these are people not our people you know so it's not special that doctors are, they are same yes [each doctor is not different they are the same]. Now you know is...we ca[n't]...you know don't have that surgery is good and that surgery [is bad] because they are same.*' [Pakistani woman age 27, 3101] [my emphasis]

This woman's perception that all GPs are 'the same' is linked to her 'race' based experience and to her lack of choice in the GP system. She uses expressions of ethnic identity to reflect on the social distance that she feels from health services that are run by 'other people' not 'our people'. Her account is illustrative of a sense of powerlessness that some of the women feel when talking about unsatisfactory experiences and racism both in health service environments and outside (see section 4.6.3). In the interview she feels that the GP does not take her seriously or listen to her. The woman quoted above has clear GP preferences. This theme is considered in more detail below.

4.3.5 Women's GP preferences

The women's attitudes toward GPs are informed by their GP preferences. These are summarised in Table 4.4. Some women feel that continuity of care is important, others stress gender or ethnicity dimensions in their relationships with GPs. The accounts indicate how the women negotiate between different GPs to enhance their access to the service and that women's GP preferences are involved in their decisions to consult the GP.

GP preference type	No. women
Continuity of care	25
See particular 'liked' GP where possible *	11
See woman GP when able/in partic. circumstances	18
Seek out and register with particular type of GP	
- Asian GP	2
- Female GP	5
<u>Unable to exercise choice of GP</u>	
- Woman GP	5
- Asian GP	1
- Asian female GP	1
- unable to see same GP	3
No GP preferences	3

*(for reasons unrelated to the ethnic background or gender of the GP)

NB Some women identify more than one preference.

Table 4.4 Women's GP preferences

Continuity of care

Continuity of care is a concern for 25 women and this affects patterns of GP use. Most see the same GP all the time and the remainder see other GPs only occasionally. Three women are uncomfortable with this arrangement, and would prefer to see the same GP all the time. Two other women like the facility of being able to see other GPs, particularly if they want a second opinion.

Women's positive relationships with GPs contribute to their expressed need for continuity of care. The interview data suggest that continuity of care enables communication between women and GPs:

'...he really cares and he knows our past history, our health of the whole family. Mainly for that reason he knows about us...you do not have to do a lot of explaining because already he knows about us.' [Sikh woman age 37, 0202]

It also suggests that a lack of continuity affects the benefits drawn from the GP and ways of using the GP. This woman feels that she cannot phone the GP for medical advice, or ask questions and take up GP time because she sees different GPs in the practice:

'Because you have to tell them all your story, your report and everything. It's your own doctor, he knows you better. He just has to look at you and remembers...but we feel were taking up too much time and just walk away and don't ask anything...

S.P.: Does that affect the way that you use the doctor?

You just can't always see the same doctors, so you don't bother asking them you know. I feel really bad about this. It's always a different doctor when you go to see them.' [Sikh woman age 42, 1002]

Continuity of care also enables women to feel confident about any treatment that may be given. For three other women, seeing the same GP means that they are confident of any medicine prescribed or are confident of getting a prescription rather than having to purchase medicine over the counter. Continuity of care affects patterns of GP use and relationships between women and GPs.

South Asian and Women GPs

Five women assay that they have actively sought out and registered with women GPs. Eighteen others try to access women GPs when they want to. Two women have sought out and another two women feel that they would like to see, South Asian GPs. In common with other studies on South Asian women and GPs (Johnson, Cardew and Cross, 1983), my study shows that women's GP preferences are not always met. The women's GP preferences provide a good example through which to illustrate the emphasis on ideas about South Asian culture over ideas about gender and 'race' difference, in explanations for South Asian women's patterns of GP use.

As noted above, more women place shared gender above shared ethnicity when describing their GP preferences. Studies show that South Asian women prefer to consult women or South Asian GPs, though the evidence is contradictory (Ahmad *et al.*, 1991a, 1991b; McAvoy and Raza, 1988; McFarland *et al.*, 1987; Donovan, 1986). Studies by McAvoy and Raza (1988), McFarland *et al.* (1987) and Wright (1983) also show that South Asian women place shared gender above ethnicity. The interview data modify conventional understandings about South Asian women's GP preferences in a number of ways.

Firstly, South Asian women do see male GPs. Many consult them because they are more easily accessible. Some women are concerned about being examined by male GPs, however, the data suggest that some may play off health problems and the body area affected against their preferences for women GPs. Other women have modified their GP preferences in response to past health service experiences. Five link their experiences of maternity care to their gender preferences of GPs. Three feel they now find it easier to see male GPs since their experience of maternity services where they were unable to see women doctors. The data suggest that there may be situations where their GP preferences are more

legitimate. One woman feels that it is only reasonable to ask for a woman GP in certain circumstances, another feels she does not want to make a fuss by asking for a woman GP all the time. The women feel more strongly if the consultation includes breast or internal examinations:

‘...if I had to go and talk about my down below problem to a man doctor that would worry me. But you get used to it once you have children it makes it more easier. Before that...it would be difficult for me to go.’ [Indian woman age 41, 2803]

Some feel that they would only choose to see a male GP in emergencies or for their children. For three women this is reinforced by the negative experiences when being examined by male GPs. They describe their feelings using words such as ‘embarrassed’, ‘shy’ or ‘ashamed’.

Secondly, the interview data suggest that women's preferences for women GPs are linked to issues of communication in the consultation and that the women's preferences for women GPs affect the role of the GP in the women's healthcare, how they use the GP and what they take to and say in the consultation. Again this modifies conventional understandings about South Asian women's GP preferences. Six women describe how they would censor (passively) what they voice in consultations with male GPs. Others say that they would only take certain problems to a male GP and that women GPs are able to identify more with their problems. The evidence suggests that women's preferences affect their patterns of GP use. Some subconsciously or consciously decide that they would not consult the GP for some health concerns if it would mean that they could only see a male GP:

‘...I don't always go to him [GP registered with] when I have got something, I go to a lady doctor or something in the surgery. There are two surgeries in there and there are quite a few women doctors now which there wasn't before though. I found that you know I wasn't going to the GP if I was having problems about something I just left it alone because there weren't any women doctors there.’ [Pakistani woman age 23, 1301]

Eleven say they feel less constrained in consultations with women GPs. These findings contrast with those of Roberts (1985) which show that women find it easier to talk to male GPs and that women GPs are perceived to be more harsh and less sympathetic.

‘...although we've been with this doctor on and off for 27 years, I still feel maybe if there was a personal problem I'd feel shy to actually speak to him, you know openly without feeling anything, whereas with a lady doctor I could...I may speak to the health visitor...or maybe the nurse...It's easier to speak to them than the actual doctor I find for personal reasons and you come out feeling better.’ [Sikh woman age 44, 0703]

'...I can talk to her more. Because she's female and I can discuss problems more private problems, I feel comfortable with her I can tell her. If I am going to see a male doctor I would probably avoid some of the issues. I'll plan it and when I get there I don't want to talk about it...She is only there once a week...It is very difficult to get hold of her but I would rather go and see her.' [Pakistani woman age 33, 0302]

My findings support those of Ahmad *et al.* (1989c) which warn that South Asian women might not consult male GPs for certain problems such as gynaecological complaints and therefore go without proper medical care. In my study, the idea of 'going without care' when women's GP preferences are not met extends to other health problems. The two women quoted above identify personal and private problems. It must be emphasised that the expressed need for women GPs is not a cultural issue specific to South Asian women. Many other categories of women negotiate the GP system and are concerned about accessing women GPs. A national study by Cartwright and Anderson (1981) shows that 21% of all women would prefer to see a woman GP on occasion and a study by Smith (1991) in Scotland shows that minority and majority ethnic groups experience difficulties in seeing women GPs.

As noted above, some women stress ethnicity over gender. This is also seen in other studies on South Asian women and GPs (Jain *et al.*, 1985). Some women dismiss the importance of shared ethnicity and four are negative about South Asian GPs. One feels that South Asian GPs treat, in her words, 'whites better' than South Asians. Another had experienced difficulties as the GP knew her family socially and this made her feel uncomfortable in consultations and another woman feels that South Asians might expect too much from South Asian GPs.

For three women, the need for South Asian GPs is an expression of the limited sense of choice that they feel in relation to other South Asian GP users in the UK:

'...Asian doctor I think is good for us and better than the other peoples...Yes in Edinburgh because is Asian community here is not really much [small]. I don't know no doctor Asian any doctor, so in every surgery the other doctor is not Asian doctor. In hospitals we don't have Asian doctors. The other towns Rochdale, Manchester they have lady doctors Asian, gents doctors Asian [Asian women GPs, Asian men GPs]...' [Pakistani woman age 27, 3101]

The need for South Asian GPs is also linked to a perception that the experience of GP care may be qualitatively different for South Asian women compared to non-Asians. Two

women are more vocal than the others who feel they would like to see South Asian GPs. They link their GP preferences to their 'race' based experiences and feel that South Asians do not have equal access to GPs compared to majority ethnic GP users. Their accounts suggest that a South Asian GP is perceived to enable communication between the participants in the consultation. The first woman sought out a South Asian GP and feels that this enabled her to avoid wider communication problems as a South Asian GP actually 'feels for her' and assists with language problems. She links her GP preference to her 'race' based experiences:

'Well there are words that in a medical sense I would not know what they are called sometimes. It is so easy to explain to her in my own language....And you find at ease....

I have always had a foreign GP and they are the best I would say because being a foreigner themselves they feel for you. I would say they have always been good to a foreigner... But I would say that GPs can be cruel just by seeing coloured and if you can't speak proper English, if you can't make them understand you, what you want to say anything else, that way they can be angry about that too because they don't understand you sometimes.' [Indian woman age 41, 2803]

The other woman is unable to see a South Asian GP and draws on her past experience in England. She feels that she would be treated more positively, listened to and taken more seriously if she saw a South Asian GP. She would also have less problems with language:

'...It would be equal but it doesn't feel it doesn't because their behaviour with us is different and the other people you know Scottish people they behave not same.

Because you know the doctor takes them seriously and listens and old peoples and youngsters as well they not behave like that with us that's why sometimes we are angry but we can't do nothing because we don't have Asian doctor. If we have an Asian doctor our problems are solved I think. First problems is our language problem here... Second problems is we are small community here that's it and we are living in Manchester I don't think so we have these problems. Scottish people doesn't like us because we are really small here and mostly you know rights are better here for them rather than us.' [Pakistani woman age 27, 3101]

Both accounts reflect racism and an exclusionary process. For the woman quoted last, her feelings of anger and powerlessness are reinforced by, as she sees it, more positive situations in other parts of the UK where a larger South Asian population has more rights in health services. These aspects of the data lead me to conclude that women's GP preferences may be stimulated more by racism and less by cultural preference.

The themes of continuity of care, negotiation in health services and the need for South Asian or women GPs are integral to an understanding of South Asian women's access to the GP

service. They shape the patterns of interaction with the GP service, what women feel they can take to the GP, how health problems are communicated and the quality of care gained. My study shows that the reasoning behind the women's GP preferences does not reflect conventional ideas about South Asian culture. Against conventional understandings, I have shown that gender and 'race' dimensions are important in women's discussions of their GP preferences. In addition, their preferences are linked to issues of communication in the consultation. The interview data suggest that women's choice of GP affects service uptake, how and why the GP service is used, and therefore the role of the GP in the women's healthcare. The next section examines the role of the GP in the women's healthcare in more detail.

4.4 Access to and use of the GP service

This section describes the role of the GP service in women's healthcare. It helps us to understand how women use the GP service and why they use GPs in particular ways. I consider the women's concerns, decision making processes and help seeking behaviours which affect their use of the GP. As argued above, one widely held assumption is that South Asians overuse the GP compared to non-Asians. I will use the women's views and experiences to challenge this assumption, to contest the pathologisation of South Asian health behaviours and to refute the implication that minority ethnic groups burden healthcare resources.

4.4.1 Deciding to use the GP service

The women make considered decisions about whether or not to use the GP service. Many factors affect these decisions, although the most prominent is the idea that the primary role of the GP is to cure ill health. Women's comments in response to questions about the type of concerns they take to the GP service suggest that the decision to use the GP is based on the idea that the GP service is used to cure ill health rather than to promote good health. Interacting with the GP service involves identifying oneself as ill/having a specific health problem to be cured, acting on it and making a decision to consult a GP.

'INT.: All the [my] problems I don't tell the GP...medical problems then I say to the GP, and that kind of help I get from the GP, [I do] not [use the GP] for advice and things.

S.P.: Not for advice?

INT.: I don't know I can get other information, I feel this is only for medical stuff.

S.P.: Would you like to use it for other things?

INT.: I don't know if I can use doctors for other things.' [Bangladeshi woman age 37, 3302]

'S.P.: Will you go to the GP for advice and information?

INT.: No. Only for the treatment I'll go to the doctor.' [Bangladeshi woman age 54, 3604]

'If I do have a problem I will go to the doctor, if I don't I won't.' [Indian woman age 33 1602]

Most women emphasise the fact that they have tried other things before seeing the GP. Table 4.5 shows that the women's health actions include using over the counter medicines, home remedies or consulting other health professionals. Adding to my findings in chapter 3, 'self doctoring' strategies are used alongside, and affect women's use of, the GP. The interview data suggest that trying other things before deciding to use the GP helps women to save time and to be 'good' patients. In addition, self doctoring strategies are used in response to past GP experiences.

Strategy	No. women
Over the counter medicines	20
Home remedies	7
Use medicines have at home	2
Complementary therapies e.g. homeopathy	2
Consult Health visitor	5
Consult linkworker	1
Family support	15

Table 4.5 Self doctoring strategies identified by the women before using the GP

Social support is also involved in the decision to consult the GP. Sources of social support such as friends or family or other health professionals act to reinforce and legitimise the decision to consult the GP as these women show:

'She [health visitor] talks to me and explains to me if I have got a problem. And explains to me what it is, not to worry too much if it's not serious, the next thing is to go and see the doctor if it's serious... She [health visitor] would just tell me about it generally, what it is and why it is done and things like that. Like if I went to the doctor I just ask. Like if she comes to see the children I can ask her other questions. It saves a visit to the doctors when somebody else might need it for something a bit more important than asking questions.' [Pakistani woman age 23, 1301]

'so I speak to them [old health visitor] before I went to the doctor, before I had something really bad...you know it's not sort of definite, but they sort of comfort you in a way you know it helps a wee bit before you go for the big crunch

S.P.: The big crunch?

Yes you've got something wrong with you.' [Sikh woman age 30, 1101]

Six women decide to use the GP to satisfy others for example, if others notice differences in their health or if others urge them to consult the GP. This woman talks about consulting for anaemia and shows how social support enables her decision to use the GP:

'And I probably will go when I start feeling dizzy or when I start feeling very very tired again then I'll go back hoping for a quick cure again you know. So again this is me being lazy.

...I know I should go and see a doctor now and make sure that I do get some iron tablets because I am feeling very tired and sometimes I do get dizzy but I will go one day soon. It's just getting myself there. And that's where speaking to my husband comes into it, he'll make sure I do get there.' [Indian woman age 33, 1702]

This woman talks about going to see the GP after a fall:

'I know the doctor won't give me anything. I went to satisfy my husband because he was a bit concerned about me...maybe if I have broke bone or something. Let the doctor have a check it, no harm done.'

She also decides to use the GP if her health problems are affecting other people:

'...if I've tried other things at home that don't work...He [husband] said go to the doctor...If it affects anybody else, my health affects anybody else I'll go...' [Indian woman age 33, 2002]

The women also reveal a number of factors which constrain their decision to use the GP. Many of these constraints are rooted in past GP experiences. Themes include women's ideas about being a 'good patient', waiting before consulting the GP, not using the GP too much and avoiding GP use. This has implications for the role of the GP in the women's healthcare and for their GP uptake.

Thirteen women feel that it is important to wait before accessing the GP. The need to wait is linked to women's concerns about the overuse of health services. They stress the GP is 'a busy person', and the need to be 'fair' to the GP [11 women]. In addition, waiting is linked to attitudes of deference, three of the 11 women feel that others might be more 'deserving' or 'needy' of GP care.

'...But for a cold maybe if I cut my finger, I never go, most people might you know. It's a waste of time, for the doctor and for you because I could leave the doctor to see others who are really sick don't just go to the doctor for a headache and...' [Bangladeshi woman age 26, 3701]

Seventeen women feel that they do not want to use the health system too much and that they do not like to bother the GP 'too much' or 'go often'. Four women criticise others who use health services 'too much'. Two feel that they do not want to depend on the GP. My findings support Roberts (1985) study on white women's GP experiences which identifies the need to be fair to the GP by not using the service too much. She also argues that the need to be fair to the GP is linked to women's anxiety about going to the surgery.

'Like we don't go to the doctor that much, like we only go when there is anything wrong with us, I go for the kids...Like you don't go to the doctor just for the sake of going you avoid, actually you avoid going to doctors you know.

S.P.: You avoid?

Yes I avoid going to doctors, because I don't like going to the doctor, I don't like taking medicines.

Yes my husband pushes me oh you...if anything is wrong with me he says 'you must go to the doctor' and I just avoid.'

She then talks about her last GP consultation for period problems:

'I didn't know what to try, I didn't know what to do so I had to go to doctor. Like I was avoiding [going], I thought it'll just get better, but like my husband said it's better to be safe than sorry you know, you must go to doctor and see what he says.' [Indian woman age 27, 3501]

Avoiding the GP is part of being a 'good patient' and allows women to be in the GPs 'good books':

'I am OK in the good books with the GP because I rarely go to a GP. But if my health wasn't right and if I had to continue going they don't like, GPs don't like if you go on and on for small [things] they think you are coming for no reason and I think that's wrong on their side, people don't want to go unless they were not well.

S.P.: What do you mean good books?

Good books how can I put it now? Well if you have a good relationship with your GP it's the best thing, best medicine I would say more or less.' [Indian woman age 41, 2803]

This woman perceives that avoiding the GP may affect the quality of care she receives from the GP:

'...maybe that's why he is treating me extra nicely or extra caring way because he knows I hardly go. If the person is going to the surgery every other day I am sure maybe GP thinks I have had enough of them.' [Indian woman age 39, 0102]

Other constraints on the decision to use the GP service are rooted in women's previous GP experiences. These relate to women's ideas about the perceived outcome of a consultation. For example, eight women decide not to use the GP if they feel they have a clear idea about the likely outcome of a GP visit, that is if they feel the GP 'will not do anything' or did not do anything in previous consultations for a given health problem. Others decide not to use the GP if they are sceptical about their relationship with the GP. My findings support those of Stimson and Webb (1975) which show that GP users rehearse beforehand what they say and what happens in a consultation. And that women's expectations about what will happen in a consultation affect GP use.

Further constraints on GP use relate to women's perceptions about prescribed medicine. Four women feel they delay seeing the GP because they are concerned about taking prescribed medicines, though another four women feel that they have to see the GP as they give better/stronger medicines than those available over the counter. Another woman feels that she has to use prescribed medicines as she is unable to find the ingredients for home remedies in the UK.

Women's experience of service organisation also affects their decision to use the GP. Six women comment on the inflexibility of appointment systems and describe how this reinforces self doctoring strategies and constrains their decision to use the GP (see section 4.5.1).

This section has shown that there are a number of enablements and constraints affecting women's decisions to use the GP service. These aspects of the data suggest that women's decisions to use the service are mediated by their previous GP experiences and by the learned strategies about how one ought to use the GP. They show that waiting before deciding to use the GP and not using the GP 'too much' help women to become 'good patients'. These findings are important as most studies address health professionals' rather than users' ideas about 'good' and 'bad' patients (Kelly and May, 1982). Other concerns that affect women's decisions to use the GP relate to their perceptions of the outcome of consultations and to service organisation. All these factors affect the role of the GP in the women's healthcare. The next section examines the primarily curative role of the GP in women's healthcare, in more detail.

4.4.2 The role of the GP service in women's healthcare

I have argued that the GP is primarily used in an attempt to find a cure for ill health rather than to prevent it. On closer examination, the accounts show that women categorise health problems and identify those worthy of presentation to the GP. They suggest that some types of ill health are more 'real' than others and deserve to be reported to the GP. This section explores two themes from the data: firstly, the idea that the role of the GP is to cure serious/bigger health problems and secondly, that the role of the GP is to assist with physical rather than non-physical health.

GPs and bigger/serious health problems

The women differentiate between health problems and perceive the role of the GP is to assist primarily with bigger or more serious health problems. In effect this reduces the role of the GP in the women's healthcare.

'INT.: I don't use often the GP whenever I badly need then I go...I don't go with little things, whenever I need then I go...

INT.: If I've got bigger problem then I have to go, but otherwise I don't go. If I've got a small problem, I don't go.' [Bangladeshi woman age 54, 3604]

Small health problems are straightforward/common complaints or those which come and go such as coughs and colds, flu, headaches, little aches, sore stomachs, and sore eyes. They are also complaints that women can treat themselves:

'...I don't know you sometimes think is it serious enough to go to the GP or not? We all think about that...do we need to really go or something we can do about it ourselves? And then let's wait till it becomes more serious.' [Sikh woman age 37, 0202]

Small health problems are also those complaints for which the women feel that the GP will not give anything. This woman shows how self doctoring strategies are used in response to past GP experience:

'If I feel I need anything really. Something is wrong with me if I feel that I need sort of like medication otherwise I won't [go to the GP]. If I feel it's something minor or he is not going to give me something or he is just going to say 'take that particular thing' then I will just go and get it myself from the chemist.' [Pakistani woman age 23, 1301]

Large or serious health problems are those that the women feel they do not understand or are new [20 women]; those problems that they do not know how to solve; those that are felt to

be getting worse [14 women]; or problems that are perceived to require medicine, especially medicine that cannot be obtained over the counter [17 women].

Although the study cannot demonstrate this fully, it is my impression from a systematic review of the data, that the increased availability of over the counter medicine has streamlined the role of the GP in the women's healthcare and impacts on their decisions to use the GP service. Eleven say they value the facility of obtaining medicine over the counter as it means they only 'bother' the GP for prescriptions, although four women are concerned about the quality and effectiveness of medicines available over the counter and feel that prescribed medicines are stronger or of better quality. The women's attitudes to prescribed medicines are considered in section 4.5.2.

'Well the medicines they give you for a cold and a cough are basically the same as cough syrup, pain killers and I tell you to rest, so why bother the doctor when you know these things yourself.' [Indian woman age 33, 1702]

'...I do believe in doctors but at the same time I feel that if we have to pills and things at home we don't have to waste their time...' [Sikh woman age 23, 1901]

Roberts (1985) shows that women learn not to bother the GP with certain things. My study suggests that notions of what to use and what not to use the GP for persist and build up over women's GP experiences. These factors affect women's subsequent patterns of GP service use.

GPs and non-physical health

The second conclusion to arise from these sections of the data is that the role of the GP is to assist with physical rather than with non-physical health. This has implications for South Asian women's patterns of GP use. In my study, as in others focusing on minority ethnic groups (McCormick and Rosenbaum, 1990; Gillam et al., 1989), the women avoid using GPs to tackle mental health problems. Like other studies focusing on General Practice populations in Lothian they also feel unsure about where to get help about psychosocial problems (Hopton and Dlugolecka, 1995). The women were asked whether they would use the GP for worries or problems at home. This aimed to find out more about how women decide to use the GP service and to lead into discussion about the use of the service for non-physical health concerns. The findings were added to by a number of unprompted discussions. Twenty one women think that they would not consult the GP for worries and

11 say they would. Eighteen women feel that they would not consult for problems at home, three women have done so, one other is unsure.

Conventional explanations for South Asian women's lack of use of the GP service for mental health concerns draw on ideas about South Asian culture. Rack (1990) for example, reports a tendency for South Asians not to report mental health symptoms. He, and others, have popularised the notion of somatisation, where South Asians do not acknowledge mental distress on account of their culture and express it through ill defined problems such as aches and pains, which have no organic basis. A number of studies challenge this interpretation (Fenton and Sadiq, 1993; Howlett *et al.*, 1992; Fenton and Poonia, 1988). For example, Howlett *et al.* (1992) compared South Asian, Afro-Caribbean and white concepts of health and illness causation and found that South Asians gave similar responses to the two other ethnic categories to questions about the notion that worry and stress are causes of depression.

In addition, my study suggests that the women perceive that it is not the role of the GP to assist with mental health concerns and that this belief is linked to their past GP experiences. With Fenton and Poonia (1988) my findings suggest that the role of the GP in women's personal circumstances is limited. Where health problems are seen to be physical and specific the women hold considerable expectations of the GP. However, they hold lower expectations of the GP when it comes to mental health problems.

The data indicate that women may feel that physical health problems seem more real or bigger than some mental health problems. The latter occupy a grey area between what are perceived to be 'proper' health problems and 'other' health problems worthy of presentation to the GP:

'INT.: She thinks if it is something to do with the health she can talk to the GP no problem, but if she thinks it is something relevant to the house or other worries or problems then she thinks I don't want to see the doctor, you know tell him...you shouldn't go and bother the doctor about it. If it is something relevant to the health then always go.' [Pakistani woman age 30, 0501].

'Yes in a way they [worries] are health issues because they make you ill because if you worry about things or there are problems at home, like you don't think straight so your health goes down...Yes in a way they are related to health issues but not straight away no, it's like yes they are related but they are not the main health issues, there are other main things. Like you've got problems with your bones and things like that, it's main health issues not your worries... So I won't go to those, I won't go to the GP for those things.' [Indian woman age 27, 3501]

‘S.P. Would you go for worries?’

...if health problem then I need to go to doctor. If another problem why I need to go...’
[Bangladeshi woman age 28, 2501]

The interview data also show that it is not that the women do not access health professionals or others to assist with non-physical health problems but that the role of the GP service is to deal with physical health problems. Four women volunteer that they have talked to their health visitors or a practice nurse about worries and stresses in their lives (Table 4.6). Others feel that they would only talk about mental health concerns if a health problem (physical) was causing worry [7 women]. This woman makes a clear distinction between the role of the health visitor and the GP in her healthcare and links it to her past GP experience:

‘...just go and visit the health visitor and they’ll have more time for you, make an appointment, rather than waste the doctor’s time if it’s not to do with a medical problem.

S.P.: What’s a medical problem?

If a person is ill. If you’re ill you’d just go to the doctor but if you had something to talk about you could go to the health visitor rather than sit and talk to the doctor when he could be seeing other patients.’ [Sikh woman age 44, 0703]

Strategy	No. women
Cope by myself	8
Turn to female friends	8
Relaxation	6
Talk to family in general	4
- husbands	3
- children	3
- mothers	3
- sisters	2
- fathers	1
Talk to health visitor	3
Talk to practice nurse	1
Talk to linkworker	1
Use home remedies	1

Table 4.6 Mental healthcare strategies outside the GP

My study shows that a large part of the belief that the GP service is not there to deal with mental health concerns, is learned from past GP experience. Six women are concerned about overuse of the health system and wasting the GPs time should they consult for mental health concerns.

Eight women say that they have avoided raising mental health matters with the GP because they do not think that the GP could do much to help, six women also feel this for problems at home. Four women question the GP's responsiveness to them and their mental health concerns. Indeed three of the women who have consulted for mental health issues and one woman who has consulted for problems at home, feel that their GPs did nothing to help them. Four women are worried about the GP prescribing medicines for such health problems. They are also concerned about over-prescribing or feel that GPs might not try to tackle the reasons why they are worried or depressed in the first place or explore the roots of their difficulties. It needs to be remembered that these are mostly the views of women who have not taken prescribed medicines for anxiety or depression.

Seven women are concerned about issues of communication should they approach the GP with mental health concerns. The case quoted below describes the difficulties in approaching the GP for mental health concerns and how these difficulties are compounded by communication problems more generally. She remembers consulting her GP about her depression which arose after an operation:

'...she just didn't give the impression that she had time for you so I would never have gone to her, telling her I was depressed.

Sometimes you don't want to talk about, you can't just come straight out and say 'this is depression', it is a thing that you can't go in and say 'right I am depressed what can you give me?'...it takes a long time for you to pluck up the courage to go and see a GP...Then more than likely you'll come out with painkillers for a headache...Sometimes you don't want to go to a doctor for depression, sometimes you just don't want to come to terms that you should go and see a doctor. Speaking with family and friends about it then mentally I think they help you take the necessary steps which is important...I am a lazy person when it comes to myself.'

She remembers and contrasts her experience with that of her previous GP:

'...although he didn't always give you a prescription he always listened and you felt that you could go to him not only for physical illness but if you wanted to you were mentally....I remember adverts when I was younger about the GP being a friend, that you could go to the GP. But some GPs you just don't feel that you can go to when you are depressed...' [Indian woman age 33, 1702]

Another woman questions the responsiveness of her GP to mental health problems. She feels that she cannot relate to her GP because the GP does not take her seriously. She has since been seeing another GP:

'I don't bother because they are not going to do anything anyway. I would like to discuss with my doctor every sort of problem...They are not really aware of mental you know health of people...due to mental illness you get affected physically, emotionally...I think it would be good if they sat down and really listened to your problems instead of saying there's not problem because you are looking fine...I would like it to be dealt with, you know a thorough sort of examination of the problem rather than having a very quick sort of on the surface problem solving. That's not problem solving...

...But I do feel that I can't really relate to them because they don't really try and really look into the problem deeper. I don't think they really take the problem of mental health seriously....I don't know anything about medicine. I feel that...your mental health is most important because if your mental health is good then internally you will be much better, you will be able to cope with things more...' [Pakistani woman age 33, 0302]

The woman quoted next feels that her GP did nothing to help and did not listen to her:

'...there is a lot more, there is more wrong with me that she never found out I think, I think you know, I think if she had spent a wee bit more time I think she would have probably realised what was wrong you know, that it was sort of mental rather than physical, you know but she never got that far...Yes I did tell her, I said 'look I am under a lot of pressure, we are not making money in the shop [family business] and we are not doing this'...but she said it was my weight.' [Indian woman age 33, 2002]

In addition, the data suggest that constraints on the use of the GP for mental health concerns are associated with constraints on choice in health services. As noted above, for some women, communication in consultations is enhanced by the availability of women health professionals. Four women link their GP preferences to the approachability of GPs for mental health concerns. My findings support those of other studies on South Asian women. Webb's (1981) telephone survey, for example, of a phone-in advice service for minority ethnic groups in London describes many requests from South Asian women presenting life crises and seeking the help of a woman GP. These findings have implications for the provision of health services to deal with mental health. They suggest that women health visitors, practice nurses and linkworkers have a role in promoting mental health services and in providing care in this area. These aspects of the data suggest that the solutions to constraints on South Asian women's use of the GP service for mental health issues lie in the structure of the service.

More recently the interpretation of minority ethnic groups' patterns of service use for mental health problems have come under greater scrutiny. To some extent my findings support their broad conclusions. Recent debates in the mental health literature examine the attributes of health services rather than those of minority ethnic health service users. These have highlighted: issues of sensitivity toward minority ethnic groups by health services

(Sashidharan and Francis, 1993); issues of the ease of diagnosis of problems based on majority ethnic language and culture (Ananthanarayanan, 1994); the attitudes of and stereotypes held by, health professionals toward minority ethnic groups (Sashidharan and Francis, 1993; Mama, 1992); and ethnocentrism and racism in health service practices (Sashidharan and Francis, 1993). It is clear that the issue of minority ethnic groups' access to health services for mental health concerns requires closer attention. To some extent my findings question the sensitivity of GPs to the mental health needs of the South Asian women interviewed. This insensitivity is both experienced and perceived by them.

4.4.3 Preferred pathways to GP care - call outs and phoning the GP

The preceding discussion shows that there are a variety of ways in which women use or predict that they would use the GP. Few studies address minority ethnic groups' use of different pathways to GP care. The women were asked about call outs and phoning the GP as possible modes of GP use. The findings show that face to face consultations are by far the preferred pathway to GP care. They also show that ideas about being a 'good' patient and the need to be fair to the GP, affect these alternative pathways.

As noted in section 4.3.3, one of the aspects that women appreciate about GPs is their willingness to visit at home. The women are generally positive about the facility of calling out GPs. As in other studies of GP care focusing on other GP users (e.g. Cartwright and Anderson, 1981), most feel that the GP would respond to a call out if asked. They reveal a number of concerns about calling the GP out, these are summarised in Table 4.7:

Concern:	No. women
Deference - others need GPs more	10
Feel not like/uncomfortable at calling the GP out	6
GPs are 'busy', little time, many patients	4
Communication is constrained as feel rushed	4
Unsure about care given by GP other than own	2
Feel confused because different GPs give different treatments	1
May not get a woman GP if consultation involves an examination	1

Table 4.7 Women's concerns about GP call outs

The women describe why they call out the GP. The accounts suggest that the process of defining a problem worthy of presentation to the GP, and the process of deciding to consult a GP is more acute at times where access to the service is constrained, especially at

weekends and after surgery hours. However, one of the strongest factors mediating GP call outs is women's 'need to be fair' to GPs.

For eight women, calling out the GP is mediated by the wish not to give the GP 'any trouble'. Two of these women stress that they do not call out the GP much, three talk about others' experiences of call outs and calling out the GP for 'small things', they show how the decision to call out the GP is not taken lightly:

'If you can't go to the GP then yes you should call the GP out, if you can then don't call the GP out. Now like we see on telly we hear on news it's very difficult for doctors also because they have got so many hours...Like if you can go to the doctor then why not, he might be busy attending some serious patient, heart attack or things like that... there are more important things. So if you can, go to the GP.' [Indian woman age 27, 3501]

Ten women feel that they call only in an emergency, 11 feel they ask for GP call outs only if necessary, that is if a health problem is 'really bad' or if they feel they have no choice and eight women emphasise that they would only do so if they could not visit the surgery. Six talk about negative experiences of call outs and feel that GPs have questioned their request too much or that the GP was angry because s/he felt the call out to be inappropriate. They are aware that GPs do not like being called out for non-urgent problems and this makes them feel uncomfortable in their decision to request a call out.

Another reason why women decide to call out the GP is that it enables them to negotiate some gender dimensions of access to GP care. For six women, call outs are sometimes a strategy to gain access to GP care if a woman has young children, and experiences constraints on mobility. This is especially the case if the women feel ill or if it is winter or night-time. Some women use call outs as a means of negotiating the GP system if they are unable to get appointments for their children.

'...if we used to be in the shop [paid work] and I had the kids, I mean I couldn't drive [if] the family wasn't well, obviously I wasn't going to take them on public transport and take them all the way to the doctors and keep them there, it would take me an hour from the shop you know, I would just wait till they [GP] came home...' [Indian woman age 33, 2002]

The decision to call out the GP is mediated by gender role obligations and associated attitudes of deference. Ten women feel that it is more important to call the GP out for others rather than themselves. Six women mention their children and two feel that other GP users need the service more. The evidence suggests that this attitude may be linked to the need to be fair to GPs:

'I am very reluctant, I would rather have not taken up their valuable time which they might be giving to another patient you know, if I can get away with it. They usually I don't know, it's a curse I think. My kids they usually fall ill on Friday [laughs]... I really feel guilty about that you know.

S.P.: Guilty, why?

I don't know because I think it might be minor for them at reception, you know doctor might think it's minor, but because it's a child you don't think it's minor...

...I don't hesitate calling them for the kids, but I wouldn't for myself.' [Pakistani woman age 33, 1402]

The women were also asked about phoning the GP as a possible mode of consultation. Pilgrim *et al.*'s (1993) work in Bristol shows that minority ethnic groups are slightly more likely than the majority ethnic group to consult a GP in person, and less likely to consult a GP over the telephone. In my study, three Pakistani, seven Indian and three Sikh women say that they have phoned the GP for medical advice. It is noteworthy that only one Bangladeshi woman had done so. Fourteen women have never tried to ask for medical advice over the telephone. Seven women including four Bangladeshi women have never phoned because of language problems, and find it easier to communicate face to face, though two Bangladeshi women say others have phoned on their behalf. Four women do not know that phoning the GP is a possible mode of consultation, three say they would if they needed to and two say that they prefer consultations face to face.

Table 4.8 shows women's reasons for telephoning the GP and table 4.9 summarises the advantages and disadvantages of consultations by phone. They show that phoning allows women to overcome some of the constraints on access to the GP service posed by their daily responsibilities and the organisation of the service. The findings suggest that there is scope for increasing the awareness of consultations by phone.

Reason:	No. women
Mediate subsequent non-GP healthcare actions	7
Minor health worries	6
Advice on medicine	4
Repeat prescriptions/results	3
Test results/certificates	2
If not understand what GP said	2
In emergency/unexpected occurs	2
Mediate subsequent GP use	3

Table 4.8 Reasons for phoning the GP

Advantages:	No. women
Saves time	8
If cannot visit GP for non-specified reason	5
If cannot get appointment	3
Circumvents gender role constraints	2
Disadvantages:	
Difficulty in speaking to actual GP	2
Going through receptionist slows down process	1
Receptionist gives answer not GP	1
Time constraints, not enough time to talk	1

Table 4.9 Advantages and disadvantages of phoning the GP

The women's pathways to GP care are affected by the need to be fair to the GP, attitudes of deference and past GP experiences. The findings suggest that call outs and phoning the GP enable the women to overcome some constraints on their GP use, in particular service organisation and inflexibility, gender role obligations and constraints on their time. Face to face consultations are by far the preferred way to see the GP. The next section examines themes in women's experience of seeing GPs face to face.

4.5 Women's experience of seeing the GP - key issues and concerns

A number of issues arose in women's accounts of their GP experience and the negotiation of GP care. The following sections, 4.5.1 to 4.5.3, discuss the central themes to arise in the interview data. These are the system of organisation, women's attitudes to prescribed medicine and issues about information and explanation. The findings suggest that these issues are linked to the attributes of health services, not to the attributes of South Asian women and their assumed culture. The findings show how the women negotiate GP care: before seeing the GP, during, and after the consultation when implementing the outcomes of GP consultations.

4.5.1 The system of organisation

Service organisation is viewed both positively, for example, having good receptionists and a positive surgery environment and negatively, for example, in terms of the inflexibility of appointments. All but one of the women attend a surgery with an appointment system. Twenty women express some form of concern about them. According to Foster (1983) appointment systems are an example of an informal gatekeeping device to control access to the GP. Sixteen of these women are concerned about how long it takes to gain

appointments, only two women relate this to their language difficulties and one woman feels this adds to her worry about her health problems. Two other women identify problems in gaining appointments with their part-time GPs. Four feel that they want to see the GP before the earliest time offered to them and that by the time they gain an appointment they feel better. This constrains their GP use. They only use the GP when necessary or try other self doctoring strategies. For this woman problems with gaining an appointment make her question her decision to consult the GP:

‘When I want to see the doctor I want to see the doctor...if you see her next week or next month you get better by that time then you don't need to see...I start getting better then [I] think my application [for an appointment] is wrong’ [Indian woman age 51, 0404]

The flexibility of appointment systems is also emphasised. Eight women say that their surgeries have an open appointment system in the morning and an appointment system at other times. Five of the women are positive about this facility, although one says she feels more rushed in open surgery. Six other women comment on the inflexibility of appointment systems and how they feel restricted, if they are unable to get consecutive appointments for themselves and their husbands or children. Inflexibility is clearly an issue for providers if they are to improve accessibility, especially for women with young children.

Six of the 13 women who comment on the waiting time in the surgery are critical. Three feel that GPs are less sympathetic to them being late than to women's experiences of the late running of the surgery. According to Roberts (1985), this is a way to exercise power over GP users. This woman expresses her sense of powerlessness:

‘...But if I [am] late in 5 minutes...they will be angry and they says ‘I am waiting for you and where you been what time is it, what is your appointment time?’ ‘Sorry you know I am coming, you know it's far...and I am walking and in my position I am pregnant...my husband he don't have time to bring me here that's why I have a later 5 minutes [I am late by 5 minutes]’...I feel very angry then because you know I can't tell the doctor...when I wait here for half an hour and you don't you know is call to me all the time...I tell my husband and he was really angry but we can't do anything you know...’ [Pakistani woman age 27, 3101]

Familiarity in, and with, the surgery environment enhances women's experience of seeing the GP. Three of the 13 women who talk about the surgery environment identify the importance of feeling known. Two women feel unknown. Receptionists play a key role in making GP users feel known in the surgery for three women. Six others appreciate the receptionist being friendly or positive as this makes them feel better. Indeed 14 of the 17 women who talk about receptionists are positive. Three women, however, feel concerned

that the receptionist is a barrier to GP care. For example, if it means discussing a health problem with him or her rather than the GP or if a woman feels that the receptionist does not trust her decision to ask for an appointment.

Thirteen women talk about the range of services that are available through the GP, with all but one being positive. Three of these women are particularly positive that their surgeries have a health visitor. Seven women feel that more information should be available in South Asian languages about the services on offer and that this would enable access. For example, one of the women says she would feel more tempted to read anything written in Bengali in the surgery and therefore be more aware. Seven others feel that they do not need translated information about the services on offer. The women stress the importance of speaking the language of health services i.e. conventional common sense knowledge about the system. This includes knowing where to go, who to see and who to ask for. This affects women's negotiation of GP care.

4.5.2 Medicines

Women's ideas about prescribed medicines are also involved in the negotiation of GP care both inside the consultation and after seeing the GP, when following the GPs instructions. As noted above, giving medicine is part of what makes a 'good' doctor (section 4.3.3). The accounts reveal a range of beliefs and responses to prescribed medication.

Studies show that GP users often expect a prescription following a consultation and that GPs frequently respond to what they perceive are patients' wishes for prescriptions. Cartwright (1983) and Stimson and Webb (1975) argue that GPs feel that people expect too much medicine but that users, however, do not expect prescriptions as much as GPs think. They also argue that through their experiences of seeing the GP, GP users become increasingly likely to expect such outcomes. All these factors contribute to the high rates of prescribing where two thirds of all GP consultations end with a prescription (Cartwright, 1983). In my study, the women express some concerns about taking prescribed medicines (summarised in Table 4.10):

Concerned about:	No. women:
Cost	8
Side effects	7
Taking too much medicine	5
Addiction/dependency	5
Drugs for anxiety/depression	4
GPs give cheap medicines first	2
Whether correct medicine given	1

Table 4.10 Women's concerns about prescribed medicines

Table 4.10 shows that some women are concerned about the wider therapeutic effects of prescribed medicines. Ideas about the dangers of drug interactions and iatrogenic disease (ill health associated with medical interventions) have attracted more and more publicity over recent years (Cartwright, 1983). This is reflected in my data which show that not all women are sure about medicines they take. Despite a feeling of trust that GPs only prescribe when necessary (see below), for some women this concern may lead them to take other steps [5 women], for example, using prescribed medicines in conjunction with other 'natural' medicines or it may lead them to avoid seeing the GP altogether [2 women].

Nineteen women trust the GP only to prescribe when necessary. Some women, however, are concerned about the GP's prescribing practices. Three women mention language problems when describing the process of getting prescriptions. Language problems affect their ability to relay health problems and, may affect their ability to gain prescriptions and unsurprisingly, their ability to receive information about them. For example, this woman gains medicine only after she is assisted by a linkworker on her second visit for a given health problem:

'INT.: If she can't explain properly to the doctor by English then she won't give the medicine and she didn't give her medicine. After that she phone me [linkworker] to come with her then after that she gave the medicine.' [Bangladeshi woman age 31, 2402]

Two others, each with three or more small children, feel that they have to force GPs to prescribe common child medicines so that they can keep them at home to be used when necessary, or when a health problem spreads among their children, so saving a visit to the GP. Both women say that they cannot afford to buy medicines that can be prescribed free for children. They also describe the difficulties in making return visits to the surgery to pick up repeat prescriptions with young children in tow.

As noted above, one aspect of the pathologisation of South Asian people's health behaviour is non-compliance with care (Bowler, 1993a, 1993b; Ahmad *et al.*, 1991b). Beardon *et al.* (1993) argue that compliance with prescribed medication is an important part of clinical practice and that compliance varies according to a number of factors, such as age, gender, the characteristics of the prescribing GP and the type of medicine. For minority ethnic groups, however, explanations for non-compliance have centred on a lack of understanding and language problems on the part of the GP user (Smaje, 1995). Compliance with care is another good example through which to examine the overlay of cultural explanations that I have criticised in this study. The interview data suggest that women's reasons for non-compliance are more complicated than language problems and a lack of understanding.

The women make the best of the help and advice their GPs give in the light of their concerns about medicines and the information given about them described above. With Bowes and Domokos (1995c) I argue that GPs' help and advice is not definitive in the women's healthcare practices as the latter are informed by women's healthcare knowledge from other healthcare arenas. Information about medicine, for example, is processed using the women's own health knowledge and past health actions. The negotiation of prescribed medication then continues away from the surgery.

Twelve women say that they always follow what the GP says about medicine and another 14 say that they negotiate and monitor health problems and weigh up the effects of taking or leaving medicine. My findings on self-modification when taking medicines are supported in other studies on Afro-Caribbean patients (Morgan and Watkins, 1988). They challenge the interpretation that minority ethnic groups do not comply with care due to a lack of understanding or language problems alone. Other factors identified include concerns about medicines and their effects on health more generally, the appropriateness of care and advice and communication with the GP. This woman is typical of another five who stop taking medicines when they feel better or when they feel it does not suit them:

'...When you're better you leave the bottle, although you're supposed to finish it...

S.P.: Why?

Because you know better [laughs], you feel better... Knowing better means you feel better in yourself, so you don't need the medicine anymore. I don't think I've ever finished a course of tablets.' [Sikh woman age 31, 0602]

Monitoring health and taking medicine is linked to women's understanding of a given health problem. Three women including the woman quoted last, describe their long term health problems such as asthma, anaemia and high blood pressure. They show that the more they know about their problem and the more time they have lived with it, the more they feel they can successfully monitor problems. All three volunteer that they take medicines less frequently than they are prescribed.

Women's perceptions of the effects of medicines on health more generally and the type of medicine prescribed also affect compliance [2 women]. In such cases non-compliance may signify a general disapproval of the GP's approach and may lead to the rejection of care received. For example, this woman describes how she analyses the GP's motives after she consulted for depression. She was given a prescription but did not start the course of medicine because she feared dependency on anti-depressants:

'...if you're so desperate you keep going back, they have to give you something right? I would rather not have something that I'd probably get hooked on anyway...' [Pakistani woman age 33 1402]

Compliance with GP help and advice is also affected by the appropriateness of advice to the women's daily lives. Two women describe themselves as 'lazy' about taking GP advice. They link past episodes of non-compliance with medication to their daily routines and responsibilities which compete for their time. Two others speak of the dietary advice that their GPs have given them, including daily diet charts. They feel unable to implement the advice because the information is inappropriate to their dietary patterns, i.e. a South Asian diet, and therefore to their needs. The implication is that inappropriate GP advice undermines the women's capacity to influence their own health for the better.

My study also provides some evidence to suggest that compliance is influenced by the quality of communication and the amount of information given in the consultation. Where women do not feel involved in the decision making process, they may be less likely to comply with prescriptions [1 woman]. As discussed in section 4.3.3, some women are concerned that GPs prescribe too readily and place less emphasis on examination, discussion, listening to users, and giving information than they would like.

'...They just say I am going to give you such and such a thing, take it such and such times, such amount...You just accept it because that's the way it is. I would like to find out what's in it, how it affects you and if it has any side effects...So I don't think they give you enough information.

They don't understand so I am not going to bother...Whereas if someone understands then you know that they understand your problem...then you can say oh well that person knows and they can prescribe the appropriate kind of treatment for me...' [Pakistani woman age 31, 0302]

Beardon *et al.* (1993) show that users' confidence in the GP service may affect compliance with prescribed medicines. I would argue that compliance is also affected by wider aspects of communication between the GP and user.

The rejection of GP advice or treatment takes place more covertly than overtly. This allows the women to exercise their dissatisfaction with GP treatment or to take some control over this aspect of their healthcare whilst leaving the GP's authority or professionalism directly unchallenged. According to Cartwright (1983), this may not always be a bad thing medically, however, it may undermine the GP-patient relationship.

This section has noted that for minority ethnic health users explanations for non-compliance have centred on lack of understanding or language problems on the part of the user. A number of factors affect compliance with GP care. Some originate in the GP arena not with the individual. This means that explanations should look not only at the attributes of the user but at the attributes of health services and users' experience of care. The effects of communication on compliance require further investigation.

4.5.3 Information and explanation

Chapter 3 showed that women are keen to gain health information and section 4.3.3 showed that giving information and explaining about health problems is part of what the women feel makes a 'good' GP. Nine women are concerned about the information that GPs give about prescribed medicines, 21 feel that enough information is given. Fourteen women feel that their GPs give them enough information about their health generally and another 11 feel that they do not. The way information is conveyed affects women's ideas about the quality of GP care gained.

Ten women talk about the manner in which information is given. Six women appreciate the GP being forthcoming with information and not having to ask for it. Another four feel their GPs are not forthcoming enough. Most women want to know as much as possible. No one says that they would rather not know about their treatment or health problems. These findings are important because as noted above, women's concerns about taking up GP time

and seeing the GP 'too often' may dissuade them from asking questions and gaining information.

The women find it difficult to criticise information giving. Many put this down to the GP's lack of time, or the need not to take up 'too much time'. It is my impression that for those women with language problems, some were less critical than they might have been because sources of social support assisted with obtaining information about medicines and helped to decipher instructions after the consultation. It must be remembered, however, that social support is not available for all inside or outside the consultation.

Language problems constrain the amount of information given about ill health [7 women] and medicine [2 women]. This may leave women feeling that they lack information without being able to ask for it, that they cannot ask about further treatment, and that they do not understand the treatment given whilst feeling they cannot question it.

Studies show that information giving to the patient by GPs is affected by social class differences. Quantitative work shows that GPs spend more time talking to those patients from higher socio-economic groups and that the higher expectations of middle class patients may be met by longer consultations (Cartwright and Anderson, 1981). They also show that middle class GP users are more confident in knowing how to gain access to services and in communicating with middle class GPs (Blaxter and Paterson, 1982). It is not possible for my study to comment on the effects of class, however, the findings do suggest that aspects of communication in the consultation, for example, being listened to, taken seriously and understood, effect women's ideas about the quality of information gained:

'S.P.: Do they give you enough information about your health problems?

No. If they heard us you know seriously they give us advice. If they doesn't they don't give us.' [Pakistani woman age 27, 3101]

'...You really have to drain things out of them rather than giving you any information at all...I don't think that they give much information as to what the situation is with your health because they don't understand a lot of things that are happening to you because they don't look into it, therefore they don't understand. If they don't understand they can't give you appropriate advice, it is not coming out. The first problem is they have got to try and listen to the problem...you'll be able to take that advice and think they understand, so they must be able to deal with it.' [Pakistani woman age 33, 0302]

Sections 4.5.1 to 4.5.3 have examined themes in women's accounts of their GP experiences. Many are not specific to South Asian women and some relate to the organisation of health

services. The next section adds to an understanding of women's experiences by focusing on the collective enablements and constraints on access to the GP service for South Asian women.

4.6 Collective factors and access to the GP service

Having described the individual factors affecting access to this healthcare arena the following sections discuss the collective factors that affect access to the GP service for the South Asian women interviewed. The evidence shows that 'race' and gender dimensions of access are central to the way that the South Asian women in my study talk about, use and experience this service. It also shows that the women manage their access to care to minimise the consequences of racism and to challenge gender inequalities in access to the GP service.

4.6.1 Gender dimensions of access to the GP service

Chapter 3 showed how obligations attached to gender roles influence women's health attitudes and actions outside health services. The data on GP use shows that the obligations attached to gender roles also affect access to the GP service. This chapter has already shown that gender role obligations shape individual pathways into the GP system (section 4.3.1) and affect pathways to GP care such as call outs or phoning the GP (section 4.4.3). It has also described how the women's GP gender preferences affect access to, and communication with, the GP. Further consideration of the gender dimensions of access to the GP is given in this section.

Interviews with seventeen of the women contain evidence which shows that gender roles mediate access to the GP to some degree. Gender role obligations shape patterns of GP use and uptake, mediate what can be defined as a problem worthy of being taken to the GP and affect women's views and experiences of GP care.

Eight women volunteer that gender role obligations affect their patterns of GP use, and how and why the GP is used. Their accounts show that the demands placed on women in their daily lives structure opportunities for accessing the GP system. They show how the women juggle multiple roles in work and household space and it is clear that these roles can conflict with their need to use the GP. Family responsibilities enable and constrain access to the GP, affect the kind of social and medical treatment the women expect from the GP and condition

the healthcare choices they feel able to make. In common with other women with children, the majority of women's concerns centre on difficulties in harnessing the GP service with children given time constraints and with restricted access to transport to the GP [4 women]. This is especially true if it means long waiting times [3 women], if the women lack social support [3 women], if they feel alone or particularly unwell [2 women] or if it is winter [2 women].

The following two examples show how gender role obligations and responsibilities are involved in women's decisions to consult the GP. The first woman is typical in talking about her multiple roles and responsibilities whilst making the decision to consult her GP. She feels that GP opening hours need to be more responsive and flexible to the needs of those in paid work and to women with children:

'Because you have still got to juggle your time between work and the kids and the kids are coming home from school. There is other things that affect you, you can't just drop everything and go to the doctor you know when they want you to go, which I think is wrong. I think you should go like the dentist down the road...is open from eight in the morning to eight at night...he probably knows that a lot of people can't fit it in during working hours, they have got to come out with working hours right. The doctors they're only open when you are working...you've got to take the day off work or you have got to make the time in your dinner hour. Then if you go you have to sit there for ages... It just makes you feel that...instead of getting the appointment you want, you're getting one when they want you to...' [Indian woman age 33, 2002]

The second woman is concerned about the time it takes to go to the GP with one school aged child and a young baby. Her feeling is that she avoids seeing the GP for herself:

'And like if anything is wrong with me he [husband] says 'you must go to the doctor, you must go to the doctor' and I just avoid. It's a pain you know with kids it's difficult you know when you have got to get them ready and take them with you.' [Indian woman age 27, 3501]

The data suggest that gender role obligations mediate the role of the GP in women's healthcare. Chapter 3 highlighted the inseparability of health and life courses (Fenton and Sadiq, 1993; Thorogood, 1989; Fenton and Poonia 1988) and showed that health actions are mediated by the position of the women in the sexual division of labour and at work. These aspects of the data show that health and life courses also intersect in women's accounts of access to the GP service. They make sense of their patterns of access to the service in terms of their gender role obligations, their daily routines and the well being of others, especially their families. Their accounts mesh with their families' concerns about, and experiences of, the GP service. This is highlighted in the accounts of five women who show how the

interests of others are taken into account when defining themselves as ill and defining a health problem worthy of presentation to the GP:

‘INT.: If she is serious then she usually goes to the doctor, otherwise if it's a minor sickness and things like that she talks to the health visitor because she finds a little difficulty [it is a bit difficult] going to the doctor with two children you know. So if the health visitor is here and it's just minor sickness like sore eyes or sore head she talks to the health visitor.’ [Pakistani woman age 30, 0501]

The woman quoted above shows how the role of the GP in her healthcare is linked to her restricted mobility outside household space. She has two young children both pre-school age. Chapter 3 highlighted the positive role of health visitors in the healthcare of some of the women (section 3.6.1). Two women make comparisons between their use of the GP and their use of the health visitor. They perceive the GP to be generally less accessible than the health visitor because it is easier for them to see the health visitor who visits at home and because s/he has more involvement and knowledge about their home lives. These findings support Bowes and Domokos' (1993) study on Pakistani women and health in Glasgow.

The gender dimensions of access are compounded by women's concerns about physical access to the GP. Six women link distance from the surgery to the effects of gender role obligations on their actual GP use. Others link physical distance to their perceptions about the effects of gender role obligations on their access to the GP. For example, some women anticipate problems if they are not close to the surgery, especially in times of emergency. These problems are exacerbated if women have to use public transport to visit the surgery or have to arrange childcare. Another three women reveal that they have changed GPs because they want to be closer to the surgery as they have young children, although two of their husbands have not changed their GPs. The evidence suggests that women manage their access to the GP to bring it in line with their own needs in relation to their families.

For two Bangladeshi women, physical access experienced through gender role obligations also meshes with ‘race’ dimensions of access to the GP service (see below). Both identify the effects of language problems along with gender role obligations on their use of the GP service. Being nearby to the surgery makes them feel self reliant and confident to use the GP. When possible they are helped by a linkworker to enable access. They add that living close to the surgery allows them to feel more confident about using it without others.

Gender role obligations affect not only the use, but also the experience of, GP care. The accounts show that the processes of exclusion from the GP service on the basis of ideas

about gender difference, operate both outside and inside the service. It is argued that health service practices contribute to the access difficulties that some women face when using the GP and deny them access to the health service resources to which they are entitled.

The women reflect upon the insensitivity of the GP system toward women with young children. Three women feel concerned about a lack of provision by the GP service for, and the negative attitudes of health staff toward, women with young children. Two others recount episodes where they have doubted the responsiveness of particular GPs toward them when they have experienced difficulties when trying to visit the GP given the multiple roles they negotiate.

The accounts show that associated with the effects of gender role obligations on access to the GP are deferential attitudes. These have implications for access to, and for securing, GP care. Deferential attitudes are also seen in women's perceptions of health (section 3.6.1). In common with other studies focusing on white women (Popay, 1992; Roberts, 1985), interviews with 12 women show that they place higher emphasis on the health of others, and see their own healthcare in relation to others. This woman is typical of those who voice attitudes of deference. She shows how it affects patterns of GP use:

'Sometimes I tend to keep these things to myself, I don't bother getting the time to make an appointment to go to the doctor. So I went and I tried to explain it's [a pain in her leg] been going on for a long time, you get the feeling they think how could you put up with it for so long...You sometimes feel you have not got time for yourself. If somebody else in the family wasn't well you'd be quick on the phone to get the doctor...For myself, I feel I'll leave it today and see how it goes you know.' [Sikh woman age 44, 0703]

Deference affects how women talk about their GP experiences [3 women] and how they describe health problems that are perceived to be worthy enough of presentation to the GP [3 women]. One conclusion from my study is that difficulties in accessing the GP service and problems in securing high quality care may be experienced by these women as a consequence of their 'own decision' to defer their own care needs in favour of the needs of their families. In addition, by emphasising that GP access is more important for their children or talking about their families' experiences, the women are able to distance themselves from their own negative GP experiences and to avoid criticism of the GP service. For example, in the interview this woman expresses deep discontent about her GP. Despite her feeling that the GP is unresponsive to her health needs, she feels that her experience is not as important as that of her children:

'INT.: She don't mind everything is all right without the doctor and she don't mind if doctor don't give anything [medicine] to her but when the doctor don't give anything to the children... she feel really angry...' [Bangladeshi woman age 31, 2402]

The data suggest that gender role obligations may mean that women face difficulties in harnessing all the benefits of care from the GP system. For example, one woman describes the strain of return visits to the GP twice in one day to pick up prescription forms after a consultation that morning, another woman finds it difficult to have to return to the GP if she cannot get consecutive appointments for her children who are suffering from, as she sees it, the same health problem. In such cases supposed overuse of the service is thus associated with the GP system itself not with ideas about 'South Asian culture'. Ideas about the women having to fit in with the system rather than the GP system adapting to assist women's access to care are to the fore in both these accounts.

Some accounts show how gender dimensions of access to the service mesh directly with 'race' dimensions of access. Both mediate women's GP experiences. This woman is typical and voices her frustration and anger about her GP experiences:

'[If] Asian lady doctor here and I tell please you are looking to my children you know I can't [and I say to her please can you look at my children]. You know she feels [for] me, she takes me seriously I think. But these people [her current surgery]...she [GP] says I can't do you have to come four o'clock and take prescription...if that child is ill and I can't you know [go] at five to GP with childrens. With the childrens I can't go it's really hard for me, that's why I don't like because they don't take...help us and give us help...' [Pakistani woman age 27, 3101]

The woman quoted above makes sense of her experience of the GP service and the lack of provision for women with young children in terms of the constraints posed by ideas about 'race' and gender difference on access to GP care. She links gender role constraints on access to the processes of exclusion from health services and this is seen in the light of her experience of 'race' difference. Gender role obligations mean that she has difficulties in harnessing the benefits of care, in this case gaining a prescription for a child, and her experience of 'race' difference is reflected in her perception that only South Asian women GPs would talk to her seriously and help her. Gender role constraints compound her perceptions about the insensitivity of her GP to the needs of South Asians. In effect, 'race' and gender difference reduce the role of the GP in her healthcare and she uses the GP perhaps less than she would like, negotiating healthcare from other sources outside services.

This section has shown that South Asian women's access to the GP is affected by ideas about gender difference. I have shown how the effects of gender role constraints on access to the GP service run right through the experience of seeing the GP from taking the decision to consult a GP, to harnessing the system, to waiting for GP care, to actually consulting the GP. I have shown how the decision to use the GP is made in the context of family needs and responsibilities. This has been highlighted in the accounts of those women who express deferential attitudes toward their own health needs and where gender dimensions intersect with physical dimensions of access to healthcare. One of the most important conclusions is that gender role obligations affect not only the uptake of but also the role of the GP in women's healthcare. This is compounded if health services are not sensitive to, and do not make provision for, women, especially those with young children.

I have shown that ideas about 'race' difference accentuate the effects of gender difference and constrain South Asian women's access to the service. The next section concentrates on the 'race' dimensions of access to the GP in more detail.

4.6.2 'Race' dimensions of access to the GP service

The accounts of the women interviewed include comments where they feel that they have been treated differently or made to feel different on the basis of their ethnic origin or supposed/presumed 'racial' difference. They reflect the socially constructed boundaries of 'race'. The following sections explore women's perceptions and experiences of 'race' difference and access to the GP service. The evidence suggests that South Asian women need to negotiate situations which do not confront other GP users and this has implications for access.

4.6.3 Women talking about racism and health service experiences

Looking at the content and the structure of the accounts allows further understanding of the effects of racism on South Asian women's access to healthcare. Section 3.6.2 examined the way in which women talk about racism paying particular attention to racism outside health services. The women's perspectives on, and experiences of, the GP service reinforce these views in a number of ways. In particular, most of the women do not use the language of 'race' or racism but speak about, and are concerned about, their own experiences or those of others in a predominantly majority ethnic Health Service. Few of the accounts show that

racism is fundamental to, but it nonetheless shapes, their experience of health services. The women vary in their views of, strategies for dealing with, and experiences of, racism in their daily lives and in access to health services.

The accounts show that women's perceptions of 'race' difference are based not only in their own experience but also in the experience of others and in their experience in other places. For example, nine accounts of unequal treatment on the basis of 'race' or ethnicity are meshed with their experiences of racism in other areas of life. The evidence suggests that racism is experienced indirectly and directly. I therefore suggest that the effects of the exclusionary structures of racism are felt to some degree whether or not a woman has experienced racism.

In looking at the way racism and access to GPs is talked about, firstly, the women refer to the experiences of others, including friends or family members, who feel they have been treated differently on account of their ethnic origins or 'race' in health services. The women are clearly concerned about the treatment of other South Asian women in health services. Secondly, following my discussion in chapter 3, the women talk about racism in other places. Place, is a marker for women to talk about unequal treatment. Eight women refer to their experience or others' experiences of racism in England or 'down South'. Some link ideas about the presence of a small community of South Asians in Edinburgh to ideas about unequal treatment. They perceive that a small number of South Asian people registered at a practice allows them to escape cultural stereotyping and labelling by the GP [4 women]. Paradoxically, a small community leads another three women to feel that the GP service is not responsive to the needs of South Asians more generally.

It is not surprising that racism is a difficult and sensitive subject to talk about. The women find it hard to articulate how racism affects their access to the GP service and their ability to make healthcare choices. Throughout my questions aimed to be sensitive to the concerns of the women. Consequently more detail on the effects of racism, and sexism on access to the service was often gained by indirect rather than direct questioning. Using the experiences of others or experiences in different places help women to make sense of racism. For example, in unprompted discussions some women reveal that they have experienced racism in health services but when questioned directly resort to using the experiences of others. Some are reluctant to admit any difficulties that they may have had on the basis of 'race' difference. This allows them to distance themselves from any personal experiences of unequal treatment

on the basis of 'race' difference or ethnicity they may have had or to back up their own experiences with those of other people. In contrast, some women talk very frankly and openly about racism. Many accounts are angry, and deeply upsetting. In some ways this gave some shared ground between the parties in the interviews.

Section 3.6.2 considered the way women talk about racism outside health services and its effects on more everyday healthcare, the interviews also show that racism outside health services affects women's perceptions of racism inside health services. Many feel that they do not expect unequal treatment inside the Health Service, from professionals, or from a service that is meant to be 'looking after you' and is there 'for your health'. One woman recounts her ideas about racism toward minority ethnic health professionals in the NHS and describes her experiences of growing up in South Africa under apartheid. When asked 'some people say that Asians are treated differently in health services...?' she replies 'it's hidden in health'. The link between racism outside and inside health services also leads other women to differentiate between types of racism. For example, another woman talks about a more 'general racism' that is 'on the streets' and racism that might be present in the health service. Below I discuss two types of racism inside health services, interpersonal and institutional. Both forms shape women's experience of using the GP service.

4.6.4 Racism and access to the GP service - the interpersonal level

The accounts suggest that 'race' dimensions of access, although structurally based, operate strongly at the individual level through the personal experience of cultural stereotyping. Women's perceptions of cultural stereotyping in their interactions with the GP, help us to understand the processes of exclusion that minority ethnic groups may face in health services. Such perceptions of stereotyping lead to feelings of anger and disappointment with the GP service. My findings suggest that stereotyping affects South Asian women's access to the service, the quality of care gained and their subsequent perceptions of, and consultations with, GPs.

As noted in chapter 1, the effects of stereotyping on access remain under-investigated (Ahmad, 1994). I reviewed studies focusing on the views of GPs toward South Asian GP users which show that GPs hold less positive attitudes toward Asian compared to non-Asian patients and that GPs may be influenced by stereotypes (Ahmad *et al.*, 1991b; Wright, 1983). These studies concentrate on the views of health professionals and the meanings that

they have for service delivery. My study focuses on the perspectives and experiences of South Asian women GP users who may experience cultural stereotypes in GP use. In common with Bowler's (1993a, 1993b) work on the use of stereotypes of South Asian women in midwifery, my study demonstrates the employment of stereotypes in service delivery and shows how South Asian women may be disadvantaged by assumptions about their health behaviours and needs. It shows how individuals negotiate, challenge and perceive stereotypes in their interactions with GPs.

The quotations below show instances where women feel that their problems have been interpreted and dealt with through inappropriate or preconceived ideas of racial identity or stereotypes. Ten women refer to stereotyping in the course of talking about their experiences of GPs. Five talk about their own experiences of stereotyping in GP use. Another four talk about the use of particular stereotypes, for example, 'Asians use the GP too much' to explain why they feel South Asian people might be treated differently in their use of the GP. One other woman hopes that stereotyping will not affect her future GP use. Five of the ten women feel that they have been 'lumped' together with other South Asian women and that this may have shaped the nature of the care that they have received.

This woman is typical of five others who perceive that cultural stereotypes have affected their consultations with GPs. She and another woman feel that they have been stereotyped when presenting mental health concerns to the GP. Both go on to stress that GPs 'should see you as an individual'. The data suggest that access is compromised when a woman's individual health problem becomes marginalised in the consultation:

'Although I do remember at the last surgery there was quite a few Asians going there and one of the doctors just *assumed* you know if you are talking about, if you're stressed up, all Asian women are. I remember that remark...They put us sort of put us into a group, all Asian women get that kind of problem, which I didn't think that was right. They should take the individual. Maybe it's helpful from their point of view, although I don't think that's right, you know sort of make you...put you into a group and say all Asian women get that kind of problem. There were a few turning up to the doctor complaining about the same thing. I think he [the GP] should treat the individual and not go by what they are you know. I mean it could be a number of reasons why they are in that situation.' [Sikh woman age 31, 0602]

Another woman talks about stereotyping and her GP use more generally. She perceives her treatment differs from other non-Asian GP users. She describes her perceptions of unequal treatment by referring to stereotypes and shows that this affects her GP use and the quality of care gained. She links a particular stereotype that 'Asians use the GP for small things' to

issues of communication with the GP. Her feeling is that she is not taken seriously by the GP, she feels angry and dissatisfied and feels that the GP fails to meet her needs and is negative. She avoids using the GP service and her sense of powerlessness makes her rely on her own healthcare outside the GP service:

‘...I feel they don't like our people I don't think because they like you know they listen the other people you know is and they can't take seriously our problems, they seriously take problems and listen to them rather than us.

SP.: Why is it different for other people?

I don't know some doctors hate our people Asian peoples I think so.

SP.: Do you know why?

I don't know...I think they thinking, they think we are you know...if I have some really small problem I going to doctor I think that's why they don't like. If I get some you know headache, you know like that small problems, I never go to the GP I take paracetamol...I feel if all the time I takes little problems to them they are fed up and they don't listen you seriously and take seriously so I think I try to go by myself...’ [Pakistani woman age 27, 3101]

The third woman links her experience of exclusion outside the health service to the culture of service provision. She talks generally about the formation of stereotypes in service delivery and feels that she has to change in health services, more than health services need to change to accommodate users. She links her exclusion to issues of communication. Further examination of communication and racism is given in the next section:

‘...all the way you change yourself. OK in your own house you can do what you want, when you go outside you go somewhere you go outdoors, Health Service...They have own rules there, sit here or do this, some people didn't do so they makes angry...They say ‘black people, Asian people they do this’...because they (Health Service) have their own culture you can't change them, change yourself...we were talking our language, they can't understand but we still understand their language, these things bothering them...That's why they say ‘blacky bastard’ and these things giving the abuse.’ [Indian woman age 32, 2202]

The three women quoted above perceive that the GP system treats South Asians in particular ways based on stereotypes. They feel that their health behaviour has been interpreted within the confines of stereotypical/assumed health behaviours of South Asian women. The second quotation above reflects the racialised construction of South Asian women's health actions where South Asian women use GPs too much and only for small health problems. It supports the idea that certain health behaviours are legitimate in health services and the widespread assumption that South Asian women are not ‘good patients’. Bowler (1993a,

1993b) discusses how stereotypes echo the negatively typified characteristics of what make 'good and bad' patients identified by Kelly and May (1982). My study adds to these findings drawing on the points of view of South Asian women themselves.

Stereotypes perpetuate the processes of exclusion from the GP service and have a number of implications for access to health services for individuals. Firstly, the evidence shows that stereotyping mediates both actual and potential access to the GP service. Racism through stereotyping reduces the role of the GP in women's healthcare. For example, the second woman quoted above receives messages that she does not deserve to be taken seriously by the GP and feels that the legitimacy of her health actions is questioned because she is South Asian. As a result of her perceptions of unequal treatment she avoids going to the GP and does not use the GP service as much as she might. Secondly, stereotyping also affects the quality of care that women feel they receive. Stereotyping impairs communication between the individual and the GP. The women quoted above feel that their messages and health problems are or were not heard by their GPs and were muted by stereotyping. This acts to undermine women's confidence in the service.

Stereotyping also has a number of implications for access to services for minority ethnic groups more generally. It masks understandings of health needs and ideas about access for minority ethnic groups. It also obscures the heterogeneity of, in this case, South Asian women's health actions and individual health needs. The issue of stereotyping in health services brings together the effects of ascribed ethnicities and ascribed health behaviours in access to healthcare. This occurs when ethnicity becomes the overriding factor in health service encounters so that women are treated on the basis of their ascribed ethnicity not their individual health actions.

This section has shown that stereotyping is a way in which discrimination based on ideas about racial difference occurs without the actions involved appearing, on the surface, to be racist. The actions of healthcare professionals may have racist effects. Stereotyping then contributes to inequalities in the health service experiences of South Asian women. The next section discusses institutional forms of racism and access to the GP service.

4.6.5 Racism and access to the GP service - the institutional level

Institutional forms of racism also exclude South Asian women and alter their access to GP care. Most women voice their concerns about institutional racism, whether they say that

they have experienced it or not. They talk about personal experiences or empathise with other South Asian women on the basis of their shared experience and are concerned about the exclusion others may face in services. The evidence suggests that institutional racism affects women's use of the service, it mediates women's knowledge of health services as a whole and the experience of GP care.

The women's concerns relate firstly, to the appropriateness of service provision for South Asian women. Section 4.5.2 discussed the appropriateness of information given by GPs about diet and argued that inappropriate health information limits women's ability to harness all the benefits of GP care. Secondly, ideas about institutional racism surface when women discuss the effects of language problems and access to the GP service. These ideas are discussed below. Many women mention language assistance when asked for suggestions to improve health services. Their comments should be read in parallel with other problems of communication with GPs beyond language reported above. I would argue that communication constraints are compounded by language constraints. The numbers below relate to women's feelings about language constraints and access to the GP whether they are currently experiencing them or not.

Access to health services requires a degree of English which many women may not have had the time, or the need, to develop (Pershad and Tyrrell, 1995). Fourteen women say that they need help with English to access the service. Another 14 are concerned about other South Asian women with language problems when using the GP service. Some women do not speak English, others do not feel confident enough in their English language abilities in health service environments, and others remember what it feels like to use the GP service with language difficulties. Three of the 14 women with language problems blame themselves for their difficulties in GP consultations.

The interview data indicate that health service practices contribute to South Asian women's access difficulties. A lack of provision for language assistance means that services do not provide for all in the same way or to the same standard. Provision for language difficulties may be considered to be a special need rooted in South Asian culture, but non-responsiveness to these (basic) needs, where services do not provide for them, or where health staff make no allowances or are intolerant of language difficulties, are related to the attributes of health services themselves and the culture existing within them.

Following the discussion in section 1.4.1, the lack of language provision is a good example to show how minority ethnic groups are blamed for their own problems. Wright's (1983) work illustrates that frequently the focus of concern is on South Asian women's failure to speak English and not on health personnel's lack of South Asian languages. This means that the onus for change is with the women not the health service (Bowes and Domokos, 1996). I would argue that language and communication difficulties relate both to the women and to services themselves. Wright (1983) notes GPs' inability or unwillingness to make appropriate adjustments for Asian populations. She found that GPs see Asians as their own 'private problem' (Wright, 1983:103) and do not look for help, for example, interpreting facilities to help communication. This leads to inadequate or inappropriate care. In addition, Patel (1993) argues that GPs are not aware of their power as gatekeepers to other services and that they may be failing their minority ethnic clients in this respect.

The interview data show that language constraints affect women's patterns of GP service use. Whilst my study cannot comment on actual consultations it does show that language constraints prevent women from deciding to use the GP. For example, above I have discussed women's pathways to GP care. Language constraints inhibit women phoning the GP, or asking for call outs or appointments over the telephone. Coping with language and health problems simultaneously makes the following woman use the GP less than she would like. She leaves the interpreter and tells me in English:

'Sometimes because of my English [I am] worrying [and] I am too ill to go to the doctor [so] I take the tablets which I have got at home.' [Pakistani woman age 35, 3402]

My study shows that language barriers may prevent women from considering using the GP. This woman is typical of the three who say that language problems make them feel less confident or scared about seeing the GP service. She remembers her problems with English language when she arrived in the UK more than twenty years ago. She shows that language problems affect access even before contact is made with the GP:

'...There should be someone there to translate or put them at ease you know to walk in anytime they want to...instead of having to worry about it if it's a different language, you know what am I going to say, what am I going to do...It does worry you...if you can't speak your own language...' [Indian woman age 41, 2803]

Language problems not only affect consultations between the GP and the woman, they may also stop women from speaking the 'language of services' and so knowing about the services available [4 women], knowing who to approach and where to go. Two of these

women and two others differentiate their ideas about the effects of language problems on access to healthcare by gender and feel that language problems are more acute for South Asian women compared to men. This perception is supported by other quantitative studies on GP views (e.g. Ahmad *et al.*, 1991a, 1989c; Wright, 1983). My study adds to this work by showing how women themselves explain this idea.

The women describe language difficulties in ways that mesh 'race' and gender dimensions of access to healthcare. Their reasoning revolves around the use of public spaces outside the home. They perceive that gender role obligations mean that women spend less time in public space than men. They feel that not only do men have more opportunities to learn English, but that they also have more opportunities to increase their knowledge about health services, how they work and what is available. This woman is typical of the four:

'...most of the men are always out anyway. They somehow learn to communicate there is no problem. The women are in the house they are speaking their own language with their children and their families and they don't learn to communicate in English....the men are probably aware of what's going on and the kind of things that are available than the women are.' [Pakistani woman age 33, 0302]

As well as affecting women's patterns of GP use, language constraints also affect women's GP experiences. Feeling less confident about seeing the GP is accompanied by feelings of powerlessness in the consultation. Six women volunteer that they cannot explain their problems to the GP and another seven women are concerned about other South Asian women's inability to explain and understand when they see GPs. The effects of language problems are compounded by different dialects, accents, the use of jargon, slang and the speed of talking. These ideas are easy to appreciate, their impact is reinforced by women's descriptions of their GP experiences. The quotation below shows how a lack of provision for language means that women may interact with GPs without communicating:

'INT.: I don't understand, he [her son] take me and doctor give me medicine and I come back...When she came first [to the UK] they used to see her, check her chest, her back and this here and they said nothing...The doctor listened to him, to her son... she is not dealing with the doctor.' [Bangladeshi woman age 64, 2604]

In this chapter I have discussed women's concerns about aspects of GP care and attitudes to the GP. Language constraints mean that two aspects of GP care targeted by the women are constrained firstly, the social skills that are valued in GP consultations and in the relationships between women and their GPs and secondly, the ability to gain advice and information. The case above shows how GP care may become 'mechanistic'. This woman

has to contend with a number of distancing mechanisms between herself and the GP in the consultation including language and social distance. She feels removed from the whole process and feels distressed but emphasises that she needs the GP, given her continuing ill health. The woman quoted next contextualises her account of language problems with reference to the exclusion that she feels in many areas of life on the basis of ideas about 'race' difference. She feels that communication problems are deeper than language problems:

'Maybe it's like you are from a different culture, a different 'race', people just like to keep away from you. Anyway they [health professionals] don't want to talk too much. It does happen even if you do speak the language, there is some kind of barrier still...it's very difficult to explain there is still a communication barrier even if you do speak the language.' [Sikh woman age 37, 0202]

In the context of little provision to assist with language, four women appreciate it if GPs make allowances for language problems. They stress that some GPs are more tolerant of language problems than others. Two others also sympathise with GPs and feel that dealing with those with language problems must be very frustrating. Fenton's (1987) findings on GP views in Bristol and Wright's (1983) study on GP attitudes to South Asian GP users, support the women's concerns. However, this does not make up for the lack of provision for language to enable access to the service.

A lack of provision for those with language problems affects women's negotiation of the GP service and means that social support is all the more important. Many women simply 'make do', or use members of the family, including children, to translate for them. They do not necessarily use family members to interpret all of the time. Five women say that they try to speak to their GPs themselves, but need others when they become confused or where consultations involve presenting bigger or more complicated health problems. They describe the frustration of, for example, being able to understand but being unable to answer the GP.

Most women feel grateful because interpreters help them to get their message across and to understand their GP. Two women feel that social support in the consultation makes them feel more comfortable and reassured because of their language problems. The use of others in the consultation, however, also leads to a number of negative feelings. In many cases the women consider these arrangements to be inappropriate.

In line with other studies the women identify a number of difficulties in relaying information to GPs when using non-professionals to help with language. For example, they are concerned about the ability of others to understand medical terminology in either language (Ahmad *et al.*, 1991b). Others identify problems in their ability to put forward problems if they only speak limited English. One woman is reluctant to reveal information of an intimate nature to her children or to members of her family, another does not want children to be present during intimate examinations. A number of factors may also constrain the information that is relayed from the GP to the individual woman. In common with Pershad and Tyrrel's (1995) findings, relatives can over identify with the women's needs and sometimes be counterproductive to the users' best interests. Two women feel that family members censor what they want to tell the GP, for example, because the interpreter feels that s/he has to put on a coping and positive face in front of medical professionals. Language problems affect the quality of care that the women feel they gain from the GP:

'...they are not professionals so that they really can't put forward the real problem. And then at the same time if the doctor is using words or jargon...stops anything, you know problems being solved.' [Pakistani woman age 33, 0302]

I have shown how interpreters may affect GP consultations. My study also reveals a number of other factors affecting the use of interpreters in women's daily lives. For example, finding another person to go to the GP may in itself be problematic. One older woman needs to visit the GP quite often but feels that she cannot ask others all the time because they have other commitments. Others face the dilemma between needing to visit the GP and having to keep children away from school to assist with language. Many are reluctant to do this and 'make do' or feel guilty that their children or family are missing out on other things. Again gender dimensions mesh with 'race' dimensions of access where women negotiate the obligations attached to gender roles to work around the institutional racism, where services do not provide for language needs.

A minority of women are able to use linkworkers to harness healthcare. Their experiences show how linkworkers act to enhance access to the GP service. The linkworkers identified are provided not by mainstream health services but by the voluntary sector. No one volunteers that they have used the Lothian Interpreting and Translation service, provided by the Regional Council, to assist with GP consultations. This woman sums up a number of feelings expressed about problems with access to healthcare and language. She feels that it is harder for her to use the GP compared to other women and feels ashamed and blames

herself because of her inability to communicate with the GP. She avoids one particular GP because she feels that she makes few allowances for her language difficulties:

'INT.: Because she can't speak like them [the GP] she is trying to make them understand but she can't speak properly... And she [her GP] [does] not want to try to listen to her and she feel really angry with that... She is avoiding her [GP] and she was giving her advice to learn English... She doesn't want to go to the doctor to her, but when in emergency she hasn't got any choice, she has to go...If she can't explain properly to the doctor...then she won't give medicine.' [Bangladeshi woman age 31, 2402]

A systematic review of the data supports my view that the women do not seem to have a choice to ask for help with language from the GP service itself. Two women volunteer that they are unsure if services exist to help with language. Another woman feels that she has no choice but to take her husband. As in other studies, for example, Bhatnagar and Ineson's (1994) work on the healthcare needs of Pakistani and Bangladeshi women in Lothian and Wright's (1983) work, there is room for improvement in women's and GPs' knowledge of interpreting provision. One woman, who now speaks English, feels that information should be made available not only in the GP surgery but outside, for example, in shops, and that this would enable the service to be used more effectively.

The accounts suggest more than just a need for interpreters to facilitate access. Indeed two of the five women who volunteer that they have interpreted for others say that they have found it a difficult job. Three of these women are second generation and can speak both languages fluently. Interpreters will not solve all the communication problems that have been shown to mediate women's access to the service. There is scope for an assessment of the role of advocates in the GP service. In line with other work stressing the value of advocates as independent health professionals (e.g. Parsons *et al.*, 1993; Hicks and Hayes, 1991), policy and resources must target forms of provision that facilitate women in their healthcare. The conclusions drawn from the experiences of women who use family members to interpret above, support the need for trained support to assist them.

Advocates would help to tackle some of the wider communication constraints South Asian women may face when accessing the GP service and put women in a stronger position to negotiate healthcare in the same way as other GP users. For example, I have shown that some women feel they need more health advice to enable them in their healthcare and that some need help in negotiating their way around health services. I have also shown that some women with language problems may find that GP care becomes 'mechanistic' if social aspects of the consultation are constrained.

The literature suggests that advocates have a number of roles besides interpreting. Firstly, advocates mediate between health professionals and women to make sure that health service users are making informed healthcare decisions. Secondly, the concept of advocacy challenges discrimination by equipping health service users with tools of information, support and language to act independently. Thirdly, advocates are able to gain first hand knowledge to assess the appropriateness of services and to identify gaps in provision alongside users (Baylav, 1994). Finally, Parsons and Day (1992) show how advocacy schemes for Turkish and Asian non-English speaking women, improved healthcare outcomes. Advocates affected clinical practice in maternity care, and that this resulted in benefits to patients and staff such as improving patients' perceptions of particular medical techniques including ultrasound.

After the interviews took place the Ethnic Minority Health Action Project was set up in Glasgow to enable access to healthcare. It provides information and support to users and health professionals (EMHAP, 1995). Future provision in Lothian might learn from the Glasgow experience before implementing any similar schemes. In addition, if provision were to be considered it needs to ensure adequate funding. During the course of this study I visited a GP practice in Bristol that used advocates. One of the advocates there relayed her uncertainty about the long-term existence of the service and its wider implications because it had not obtained centralised funding and was funded from a number of sources.

This section has shown that access to the GP service for South Asian women is constrained by institutional racism and interpersonal racism operating through stereotypes. For South Asian women as a group, racism leaves health needs unmet. For individuals, it may affect healthcare choices, the way an individual decides to use the GP and reduce the actual and potential role of the GP in his/her healthcare. This section has also shown that 'race' dimensions mesh with physical and gender dimensions of access to the GP service. Racism then is not the only factor affecting access to the GP service. On health service users' experience of racism, I have shown how the women interviewed make sense of racism, and have used their experiences to increase understandings of racism as a constraint on access to health services. Racism operates outside health services but the evidence shows that racism is reproduced through the attributes of health services. This analysis has shown that on the surface, discrimination on the basis of 'race' or ethnicity may not appear to be intentionally racist, but it has racist effects that change the access of a particular category of women to an appropriate GP service (Bowes and Domokos, 1995a). For example, where services do not

provide to assist with language, then racism occurs by omission, contributing to inequalities in access to healthcare for South Asian women. On service provision, the accounts illustrate the need to improve patchy ethnically sensitive provision. In doing so it should learn from and assess other projects seeking to enhance access to healthcare for minority ethnic groups. Some of my conclusions do not seem to be new, for example the need for language provision. This illustrates the persistence of the marginalisation of South Asian women's healthcare needs and inequalities in provision.

4.7 Conclusion

This chapter has examined the issue of access to the GP service, my second healthcare arena. I have investigated women's attitudes to GPs, pathways into the service, the role of GPs in the women's healthcare and a range of issues in women's experiences of the service.

The findings add to those in chapter 3 in two ways. Firstly, these aspects of the data challenge explanations for South Asian women's patterns of GP use that have emphasised conventional ideas about South Asian culture and the pathologisation of South Asian women's health behaviours. These ideas have dominated policy debates and reinforced a view that South Asians are a burden on health services (section 1.4.2). For example, it is clear from this research that South Asian women do not overuse or make 'inappropriate' use of the service and that they do comply with GP care. Secondly, adding to my findings in chapter 3, women's GP stories were told as part of life stories. The data in this healthcare arena have also shown that women's health and life courses cannot be separated.

The accounts have revealed a variety of constraints on South Asian women's access to the GP service. One of the most important conclusions is that South Asian women's patterns of GP use are linked to the attributes of the GP service, rather than to the women's culture as conventionally thought. A related conclusion is that women's past experiences of the GP service affect their subsequent patterns of service use. These issues surfaced in women's discussions which revealed the learned patterns of GP use and their ideas about being a 'good patient'. The latter emphasise that users should not use the GP too much or too often and should avoid seeing, and be fair to, the GP. I have suggested that the learned patterns of service use affect the role of the GP in South Asian women's healthcare, and that the role of the GP is primarily to cure physical health problems and to cure serious or bigger health problems. These findings are important for a number of reasons. Firstly, because chapter 3

highlighted women's concerns about stresses and worries in their lives. These aspects of the data indicate that women are constrained in their use of the GP service for non-physical health problems. Secondly, because the GP is a gateway to other sources of care as well as to advice and information, and thirdly, because of the shift in the nature of primary care from cure to prevention. Women's ideas about the use of the GP service centre around the GP's capacity to cure health problems rather than prevent them, for example. Finally, my findings are important as they challenge understandings of South Asian women's access to the GP service which have centred on the attributes of GP users rather than on the attributes of the service.

A number of other factors constrain South Asian women's access to the GP service. The theme of communication ran throughout the findings and has been shown to affect women's patterns of GP use and their GP experiences, their relationships with GPs, GP preferences and their compliance with care. These findings show that the constraints on communication affecting access to this service are much broader than language constraints which are commonly emphasised in explanations of South Asian groups' access to healthcare.

Access is also constrained by ideas about 'race' and gender difference. These structural constraints affect women's: attitudes to GPs; GP preferences; patterns of registering with GPs; decisions to use the GP service; and their experiences of the GP service, in particular, the role of the GP in their healthcare.

In spite of such constraints the women are not rendered passive recipients of healthcare. Access to the service is enabled by women's ability to negotiate the GP system. They try to harness the type and quality of care that they need so that access to the GP service takes place on their own terms as much as possible. They negotiate GP care: before the consultation, for example, when accessing preferred GPs; during the consultation, for example, when coping with the system of organisation and gaining prescriptions; and after the consultation when acting on the GP's advice or taking prescribed medicines. Another factor enabling access to the service is social support. The findings have shown that social support takes on a more advisory role than in the previous healthcare arena where it provided more hands-on support for women in health and in ill health. This is illustrated by my findings on language support, gaining and complying with prescribed medicines and women's means of learning about the GP service. Ideas about social support run through

women's perceptions and experiences of the GP service. For analytical reasons I have included them throughout the sections of the chapter rather than in a single section.

This chapter has challenged the pathologisation of South Asian women's health behaviours in relation to GP use. The next chapter focuses on South Asian women's access to cervical cytology, where it is widely assumed that South Asian women underuse the service on account of their culture.

Access to cervical cytology and South Asian women

5.1 Introduction

This chapter explores access to cervical cytology services for South Asian women, which is my final healthcare arena. This healthcare arena is a good example through which to challenge understandings of access which have focused on the attributes of women, rather than on the attributes of health services. The accounts of the women in this chapter describe their patterns of uptake - how they use the services; why they use services in particular ways; and their perceptions and experiences of cervical cytology. The analysis builds on the findings of chapter 3 which showed the healthy behaviours of South Asian women. Cervical cytology is a preventative service which involves the use of health services to help women to keep healthy. The analysis also builds on the findings in chapter 4 which examined access to the GP service which is a route to preventative as well as curative healthcare provision. Once again the accounts show that the enablements and constraints on access to cervical cytology services are meshed with women's accounts of their daily lives. As in the two previous empirical chapters, this chapter considers the individual and then the collective factors affecting access to cervical cytology services. It shows that ideas about 'race' and gender difference mediate all levels of access.

5.2 Background: South Asian women and access to cervical cytology

The following sections outline the background to my findings. They examine the need for further debate about access to cervical cytology (section 5.2.1), understandings about South Asian women and access to the service (sections 5.2.2 and 5.2.3). Next they outline the concept of screening, the epidemiology of cervical cancer, and examine arguments for and against the service (section 5.2.4) and the policy context and changes in service provision (section 5.2.5).

5.2.1 The need for further debate about access to cervical cytology

Although the literature acknowledges that there are differences in the uptake of cervical cytology services between categories of women, it has concentrated on age and class differentials (Schwartz *et al.*, 1989; Bowling, 1989). Few studies have been designed to explore access to cervical cytology services for categories of women occupying other social positions, for example, minority ethnic women. One major criticism of the existing literature on cervical cytology is that it mainly centres on service uptake and on women's knowledge of cervical cytology, *rather* than on their perspectives on, and experience of, the service. As I have argued in chapter 1, these ideas are integral to an understanding of access to healthcare for South Asian women.

The need for a broader conceptualisation of access beyond measures of uptake, is signalled in the general literature on access to cervical cytology services. Whilst this work recognises that more research needs to be done to increase the uptake of cervical cytology services by all women, it also shows that there is a dearth of information on women's experience of cervical cytology, for example, information on the factors that encourage women to have a test, or on the views and experiences of women who have never had or rarely use cervical cytology (Gregory and McKie, 1992; Senior and Williamson, 1990).

Studies show that further work is required in order to explain patterns of access from the point of view of service users themselves (McKie, 1995; Gregory and McKie, 1991). I will argue that if we are to make progress in thinking about access we have to find ways of understanding the views of women and their concerns about the attributes of the service.

Some literature does urge a further understanding of the attributes of services and their effects on access to care, however, it concentrates on the perspectives of service providers. A particular focus of interest has been the logistics of screening and their effects on women's uptake of the service. In the main, studies have focused on service organisation and management, however, this is from the service point of view, rather than from the user perspective. The significance of this work cannot be denied in its contribution to the establishment of a national cervical cytology screening programme (Bowling and Jacobsen 1989; Eardley *et al.*, 1985; Chamberlain *et al.*, 1984). However, it also shows that problems with service provision and management have continued to the present day. Studies have identified deficiencies in: the call and recall system, the management of computer invitations for screening, and the generation of call and recall lists at the GP or Health Board

level. The latter include problems with lists containing the addresses of minority ethnic women (Bradley and Friedman, 1993) and transient inner city populations (Anon, 1991; Doyle, 1991; Smith, Elkind and Eardley, 1989; Bowling and Jacobsen, 1989).

Importantly, the studies highlighted above link patterns of uptake to the way that health services are provided. The identification and continuation of service organisational and management problems suggest that to be appropriate and effective, services need to adapt to the needs of the women that they serve (Eardley *et al.*, 1985). This means that cervical cytology services must be provided in ways that are sensitive and flexible to women's needs. In terms of my study, it follows that service provision needs to be ethnically sensitive and appropriate to be effective in enhancing South Asian women's access to cervical cytology.

This chapter is concerned with the need for further debate around access to cervical cytology services. So far I have identified differences in uptake among different groups of women. Next I examine the literature on South Asian women and cervical cytology provision. This helps to strengthen my argument that understandings and questions about access should be informed by the perspectives and experiences of women themselves.

5.2.2 The need for further debate about access to cervical cytology services for South Asian women

The existing literature on access to cervical cytology services and minority ethnic women is limited, indeed few studies address minority ethnic groups' response to screening provision more generally (Bhopal and White, 1993). This section reviews a small number of studies which have focused on cervical cytology services and South Asian women. It raises a number of specific issues about the uptake of the service and women's pathways into, and opportunities for accessing, the service. Section 5.2.3 adds to this discussion and uses this healthcare arena to highlight a number of general issues in the literature on minority ethnic groups and healthcare.

Questions of access to cervical cytology screening are especially important among this group of women. South Asian women's rates of service uptake have been the subject of some debate and epidemiological studies show that rates of cervical cancer vary among social groups.

A number of studies point toward inequalities in access to cervical cytology for South Asian women. The picture, however, is contradictory. In contrast to the literature on the GP service where South Asians are seen to be service abusers, studies refer to the widespread assumption that South Asian women as a group have low uptake rates of cervical cytology services and preventative health programmes (Bowes and Domokos, 1995a, 1993; NAHAT, 1995; Bradley and Friedman, 1993; Anon, 1991; Baker *et al.*, 1984). Some studies have confirmed relatively low uptake rates (Pilgrim *et al.*, 1993; Hoare *et al.*, 1992; Doyle, 1991; McAvoy, 1989; McAvoy and Raza, 1988), especially among younger and older South Asian women (HEA, 1994). Bradley and Friedman (1993), however, show similar rates of uptake between older non-Asian and Asian women in Oldham. They question the use of 'race' or ethnicity as an independent variable in measures of service uptake.

Other studies show that the opportunities for accessing the service may be different for South Asian women compared to other women. Several studies indicate that South Asian women have poor knowledge of cervical cytology and that they are less likely to have had a test in the past than majority ethnic women (Bradley and Friedman, 1993; Doyle, 1991; Firdous and Bhopal, 1989; McAvoy and Raza, 1988). Bradley and Friedman (1993) show that South Asian women may have had fewer opportunities to attend in the past than non-Asian women. This is supported in work by Firdous (1987) and Firdous and Bhopal (1989) which compared the views and experiences of Asian and non-Asian women who attended the same GP clinic. This showed that South Asian women were less likely to have had a test during obstetric care than non-Asian women. In addition, another study by the HEA (1994) shows that some South Asian groups are less likely to have been encouraged into screening by a health professional than majority ethnic women.

Such findings highlight the need for studies to examine South Asian women's pathways into cervical cytology. Following on from my findings in chapter 4, it is not enough to ascertain *if* women use services, studies must be designed to examine how services are used and why they are used in particular ways, if at all.

Information on the incidence of cancer among minority ethnic groups is limited (Harding and Allen, 1995; Smaje, 1995). The need for further debate about access to cervical cytology services and South Asian women is also supported by some epidemiological evidence that shows differences in the rate of cervical cancer among groups of women both in the UK and in the Indian subcontinent. Of particular importance to my study, is some

tentative evidence which shows that cancer of the cervix appears to occur more frequently in Asian compared to 'non-Asian' women. This includes Donaldson and Clayton's (1984) study in Leicestershire. Also, in the west of Scotland, Matheson *et al.* (1985) conducted a retrospective analysis of a range of cancers from 1961 to 1981. Their study identifies lower rates of lung cancer and breast cancer among Asian compared to non-Asian women but provides evidence to show that rates of invasive cervical cancer may be four times higher for South Asian women than for other women. The incidence rate was found to be much closer to that of Bombay.

Other studies, however, show no difference in the incidence of cervical cancer (McAvoy, 1989; McAvoy and Raza, 1988) or a lower incidence of invasive and *in situ* cervical cancer (Barker and Baker, 1990) among South Asian compared to non-Asian women. Some research shows that mortality from the disease is lower in those born in the Indian subcontinent than in the general population (Harding and Allen, 1995; Balajaran and Bulusu, 1990), though the impact of generation or migration on prevalence and mortality rates remains unclear.

Unfortunately little is known about rates of cervical cancer in the Indian subcontinent. Some evidence though does give cause for concern and would seem to undermine the findings of Balajaran and Bulusu (1990) and Harding and Allen (1995) cited above. It is known that cervical cancer occurs most commonly in less developed countries, where it is the second commonest female cancer after breast cancer (CRC, 1994). Luthra's (1986) study for example, showed that 16% of the world's total of new cases occurred in India alone.

5.2.3 Culture, 'race' and gender in access to cervical cytology services for South Asian women

The key issue of South Asian women and cervical cytology can be used to illuminate a number of general issues in the literature on South Asian women and health. As noted above, it is widely assumed that South Asian women as a group have low uptake rates of cervical cytology. There is a need to locate such accepted understandings within wider debates about access to health services, minority ethnic groups and health and women's health more generally.

As noted in chapter 1, cervical cytology is a good example through which to explore both the 'race' and gender dimensions of access. The gender dimensions are immediately apparent. Cervical cytology is a preventative health service which recognises the unique health needs of women and is commonly perceived as a women's health issue (McKie, 1995). Policy recommends that women undergo screening regularly for most of their adult life.

The 'race' dimensions of access are also apparent. The issue of South Asian women's access to cervical cytology demonstrates the persistence of the role of cultural factors and the influence of assumed and 'problematic' South Asian cultures in explanations of access to healthcare. South Asian culture is widely assumed to generate constraints which deter South Asian women from attending, mean that cervical cytology is a cultural taboo (Bowes and Domokos, 1995a) and allow little understanding of cervical cytology. This has meant that explanations of South Asian women's poor uptake rates and experience of the service centre on the widely held assumption that South Asian women do not comply with or are not motivated to use, cervical cytology services (McAvoy, 1989; McAvoy and Raza, 1988).

The issue of South Asian women's access to cervical cytology reflects the construction of minority ethnic groups' concerns and the pathologisation of their culture, health beliefs and behaviours, where groups are seen to deviate from 'good' health and healthcare and are then blamed for their health problems. Where ideas about cultural constraints are seen as the main barrier to access, the shared gender and the 'race' dimensions of access to cervical cytology remain submerged. Such ideas will persist as long as the concerns of South Asian women remain unheard. Research into women's views and experiences of cervical cytology has excluded South Asian women (Bowes and Domokos, 1995a, 1993) and played a part in limiting understandings of South Asian women's access to the service. Their needs have been constructed or ignored on the grounds of cultural sensitivity and this has led to caution in approaching such issues (Gregory and McKie, 1990).

From the discussion above, it is clear that the effects of South Asian culture, 'race' and gender difference on access to cervical cytology require more investigation. I have argued that research must be designed to examine and understand women's own views, rather than predetermine their concerns, assume their preferences or take for granted the existence of culturally based taboos.

5.2.4 Background: The concept of screening

To develop a discussion of the questions framed for South Asian women it is necessary to review the general literature on cervical cytology. A number of key points emerge about the concept of screening and rates of cervical cancer.

The concept of screening focuses on health rather than disease. It supports the idea that disease is kept in check by constant vigilance. Screening aims to look at the potential for disease, before it declares itself (a pre-disease condition), or to diagnose disease, so that further intervention can take place to stop its development. The rationale for early intervention is that this reduces mortality and morbidity and is more efficient than waiting to intervene at a later stage in the development of disease (Posner, 1993). The assumption is that without medical intervention, the disease is likely to progress and that the 'intervention will do more good than harm' (Posner, 1993: 56).

Screening provision has become a health service priority in recent years and has resulted in more people being screened, for more conditions, over greater spans of their lives (Marteau, 1990). It has, therefore, become increasingly 'acceptable' to submit vast numbers of people to medical interventions to detect, and hopefully control, abnormalities in a minority of them. Women in particular, have been increasingly encouraged to undergo screening regularly (McKie, 1995). Pressure is put on them to undergo regular gynaecological examinations and physical examinations of their breasts (Skrabanek, 1990a).

Cervical cancer is potentially one of the most preventable cancers. It is one of the few cancers that can be recognised at a pre-cancerous stage through screening. Cervical screening is an example of secondary prevention. It does not prevent the development of early stages of the disease but seeks to detect cell changes in the area of the cervix which may or may not be pre-cancerous. In terms of disease prevention, early detection has been shown to increase chances of successful treatment, though there are differences in survival prognoses at different levels of the disease.

Patterns of cervical cancer

An examination of both prevalence and mortality rates of cervical cancer provides further background to my findings. Further detail is given in appendix 4. Cervical cancer is the eighth commonest cancer in women in the UK and the commonest cancer among women

under 35 (Austoker, 1994; CRC, 1994). Studies show that mortality rates from cervical cancer in the UK are among the highest in Europe (Esteve *et al.*, 1993). In the UK in 1992 1860 women died from cervical cancer giving a death rate of 63 per million women (CRC, 1994). Mortality rates from the disease remain constant. This implies that screening appears to have had little influence on mortality (Murphy, Campbell and Goldblatt, 1987), however, the incidence of cervical cancer is increasing (Austoker, 1994; Chamberlain, 1984) and it is widely believed that the increase in mortality might have been much greater if screening were unavailable (Austoker, 1994).

A number of risk factors have been identified centring around socio-economic status, age, sexual transmission and screening status. Studies show that women in social classes IV and V attend less often and are more likely to die from carcinoma of the cervix than women in social classes I and II (Evans *et al.*, 1989). Mortality and incidence rates have also risen for women aged 25-34 (CRC, 1994). It is the most common cancer among this age group accounting for 25% of all cancers (Austoker, 1994; CRC, 1994). Between 1960 and 1980 the incidence of cervical cancer among this age group increased by 200%, while the mortality rate increased by 72% (ICRF, 1995). The pattern, however, remains that incidence rates and mortality increase with age (CRC, 1994; Eardley *et al.*, 1985). Ninety five percent of all deaths from cervical cancer occur in women over 35 (CRC, 1994).

Such incidence rates cannot only be attributed to the screening programme and relatively high rates of screening among young women. The causes of cervical cancer remain unknown, however, two types of Human Papilloma Virus (HPV) transmitted through sexual intercourse and changes in women's sexual behaviour have been widely associated with the development of the disease (CRC, 1994; Murphy, Mant and Goldblatt, 1992; Beral, 1974). Another risk factor may be screening status. It is asserted that undergoing one screening can reduce significantly the risk of cervical cancer developing (McKie, 1995). Studies have shown that before 1988 the majority of women with carcinoma had never been screened (CRC, 1994).

Costs and benefits of cervical cytology screening

Cervical cytology screening presents a number of benefits and disadvantages for women. A number of key themes are considered here. Further detail is given in appendix 5.

The dominant view is that cervical cytology has a number of wider health benefits for women. Apart from helping to prevent cervical cancer and to reduce morbidity and mortality through detection and treatment, cervical cytology is seen to help women in the active management of their health. The service is promotive, enhancing healthy behaviours, as well as preventative, helping women to keep healthy. Preventative medicine urges women to practice healthy behaviours, including the use of health services to keep healthy, to take responsibility for their own health and to accept information on health damaging behaviours (Holland and Stewart, 1990).

Health professionals have paid much attention to the 'failure' of women to attend for screening (Foster, 1995; Pearson and Spencer, 1989; Eardley *et al.*, 1985). Explanation has centred on the attributes of women. If a woman does not participate she forgoes the wider health benefits described above, is labelled a non-complier and is considered to be 'irresponsible' in terms of her own health.

In the wider context, if attending for cervical cytology screening is part of 'good health behaviour' this entails a number of changes from conventional patterns of service use. Firstly, attending for screening requires those who presume themselves to be healthy to interact with health services at intervals and within age limits defined by health professionals and policy. The service 'is seeking to find potential patients to offer help rather than patients coming with problems for which they are seeking help' in a population wide programme (Posner, 1993: 55). Secondly, the use of the service entails a change in women's perceptions of the role of health services in their healthcare from being used in ill health to be used in health.

The minority view is that screening is inherently ineffective. Commentators have debated the contribution of cervical cytology to the reduction of cervical cancer as inequalities in uptake persist (McCormick, 1989; Eardley *et al.*, 1985). On the user side, they have debated the wider health benefits of screening including the uncertainty of benefit and harm that may be associated with screening if it is undertaken with little knowledge of its purpose, accuracy and implications (Skrabanek, 1990a, 1988; Marteau, 1990). The harm-benefit balance posed by such interventions, including the personal impact of screening on women's physical and psychological health, has been debated. Further, the effects of screening on subsequent health behaviour, where screening may give false reassurance to women or constrain healthy behaviour in the long term and where women rely on the safety-net of

health professionals to identify and solve health problems (Holland and Stewart, 1990) have also been the subject of concern. Others stress that not enough is known about the relationship between minor abnormalities of the cervix and cervical cancer to be able to claim that detecting abnormalities prevents cancer (Posner, 1993; McCormick, 1989). These studies discuss the accuracy of results and the implications for false positive and false negative results. On the service side, studies have criticised the cost-effectiveness of the procedure (Skrabanek, 1990b; McCormick, 1989) and follow-up treatment (Foster, 1995) and cost-effectiveness linked to overdiagnosis (Foster, 1995) (see appendix 5).

Cervical cytology screening like any other medical intervention, presents advantages and disadvantages for women. Much of the debate has been framed in 'medical terms'. This reinforces the need for women to inform the debate. It has become accepted and part of 'good health behaviour' to submit for investigations for illnesses for which one shows no symptoms, thus detecting possible abnormalities that may undergo specialist treatment. The next section examines the policy context of cervical cytology provision.

5.2.5 The policy context and the organisation of cervical cytology services

A number of key points emerge in the literature on screening policy these also inform my study and add to my discussion of women's health policy in section 1.5. Further explanation is given in appendix 6.

Cervical cytology screening is a valuable part of preventive healthcare provision (McKie, 1995) and is part of a policy agenda on women's health. In 1988 the NHS Cervical Screening programme was established along with a call and recall system. Current policy emphasises the regularity rather than the frequency of screening. In Lothian current guidelines are set to screen all women between the ages of 20 and 60 every three years. Changes in provision have been brought about through the introduction of targets and shifts in the location of cervical cytology provision. The English Health Strategy 'The Health of the Nation' (DoH, 1992) pledged to reduce the incidence of invasive cervical cancer (appendix 6) by at least 20% by the year 2000, from 15 per 100,000 population in 1986 to no more than 12 per 100,000. The Scottish strategy, however, does not set targets for mortality reduction (Scottish Office, 1992) but stresses the preventable nature of the disease. In addition, health service restructuring has led to shifts in preventative healthcare away from specialist centres into more widely available primary healthcare services. This is part

of a wider policy emphasis on the role of General Practice in health promotion and illness prevention. Financial incentives and targets of screening uptake set in the GP Contract (1990) now mean that this type of provision is linked to GP remuneration.

Targets and uptake rates, however, do little to explain access patterns, to explore constraints on access to cervical cytology or to link poor uptake to wider debates in minority ethnic groups' access to healthcare. Having outlined debates about culture, 'race' and gender difference with regard to screening, the concept of screening and the policy context, the following section introduces my findings.

5.3 Women's attitudes to cervical cytology - key issues and concerns

In presenting the findings I will focus on women's pathways into cervical cytology (section 5.3.2), the formation of women's attitudes to and beliefs about cervical cytology (sections 5.3.4-5.4.3) and on key issues in women's experience of cervical cytology (sections 5.5.1-5.5.5). In sections 5.6.1-5.6.6 I examine the collective enablements and constraints affecting South Asian women's access to cervical cytology services. The findings reflect the wide range of experiences of, and perspectives on, cervical cytology in the accounts of the South Asian women interviewed.

5.3.1 Women's attitudes to talking about cervical cytology

Given the intrusive nature of cervical cytology testing and the need to be sensitive to the views of the women, my extensive ground work carried out before the interviews (section 2.4) and discussions with key informants, interpreters and members of voluntary groups suggested ways of approaching the topic and contributed to the success of my questioning about cervical cytology. The majority of the 35 women questioned about screening talked quite freely about their views and experiences. Only one woman seemed embarrassed to talk about her experiences. These findings provide an initial challenge to the widespread assumption that access to the service is constrained by the taboos and mores of South Asian culture.

Information was asked for about women's perspectives on, knowledge of, and experiences of cervical cytology services especially their first and most recent experiences. Of the women questioned, all but one had undergone one or more tests. My findings, therefore,

relate to the views and experiences of regular and irregular attenders rather than non-attenders. The study aimed to ascertain the women's attitudes and experiences as they saw them. It may be that some of the women had undergone additional screening but were unable to recall their experiences, for example, when screening had occurred as part of examinations during their maternity care. In addition, some of the women may have confused their experiences of cervical cytology with other gynaecological interventions but it was not possible to be sure without access to their medical files from an array of different health services. Every effort was, however, made to clarify that the women were talking about cervical cytology screening.

5.3.2 Women's pathways into cervical cytology services

Table 5.1 shows that of the 34 women who have been tested, all but three have had a test within the last 4 years. This finding is important as studies show that having a previous test is a significant factor in the uptake of an invitation to have a test (Pierce *et al.*, 1989; Eardley *et al.*, 1985). Indeed of the 25 women who have had more than one test, 14 say that they have been screened regularly. Of the nine women who have had only one test, four are in their twenties and so had only recently become eligible, and five know that screening needs to be done regularly every three years (see also section 5.5.1).

No yrs since	No. women
0-1 yr approx.	14
1-2 yrs approx.	5
2-3 yrs approx.	9
3-4 yrs approx.	3
4-5 yrs approx.	1
5+ yrs	2
Never tested	1

Table 5.1 Years since most recent test

Table 5.2 shows that 26 of the 34 women had their first test during their twenties. This is within or before the age range of women with fastest growing rates of invasive carcinoma of the cervix (CRC, 1994; Scottish Cancer Registration, 1983), and in line with systematic screening and uptake rates recorded for other categories of women (Schwartz *et al.*, 1989).

Age at first test	No. of women
20-30	26
30-40	3
40-50	3
50+	1

Table 5.2 Age at first test

Table 5.3 summarises the women's variety of pathways into cervical cytology services. Most have experienced screening as part of another medical service. Of the women who have had multiple tests, 13 had them at a post-natal check-up. Of the 25 women who have been screened more than once, 13 have been screened opportunistically. Four of the women who have only been screened once have also been screened opportunistically. Opportunistic screening has been criticised for a number of reasons including its limited success in enhancing uptake by women who are most at risk, especially older women (Eardley *et al.*, 1985), also its negative effects on women's levels of knowledge about testing and on the regularity of uptake (Gregory and McKie, 1992, 1991). My findings suggest that opportunistic screening still plays a role in the uptake of the service for some women.

Health service used to screen women	Women tested more than once		Women who have had one test only
	First Test	Most recent	Test
On Registering with GP surgery	1	3	0
Ask GP	0	2	0
Letter from GP surgery	3	8	3
Opportunistic - GP	4	5	4
Postnatal check-up - GP	4	2	2
Postnatal check-up - Hospital	7	0	0
Hospital other	1	2	0
Opportunistic - FPC	3	1	0
Ask FPC	1	1	0
Mobile unit	0	1	0
Can't remember	1	0	0

Key: FPC = Family Planning Clinic

Table 5.3 Cervical cytology services used by the women

Thirteen of the 25 women who have had more than one test, have been tested at more than one screening site. Of the 34 women who have been screened, 30 have been tested at the GP surgery. These findings support the emphasis on preventative medicine in primary care (section 5.2.5). Three of the women have been screened at their own request, at either their first or most recent test.

The accounts include reasons why women attend for screening. The majority of reasons given are passive, for example, women are sent for testing by the GP, in response to a letter, at the suggestion of a doctor, and emphasise that screening is official. Many women attend for screening in response to their general practitioners 'interest' in screening and their accounts reflect an obligation to attend. This theme carries through to the women's attitudes toward cervical cytology (see also section 5.3.4)

'She call all the time when she want smear test and I go for smear test.' [Pakistani woman age 27, 3101]

'...as far as I know I get a letter now and they do it for me that's good. I don't miss it anyway when it comes.' [Sikh woman age 42, 0903]

5.3.3 Individual factors and access to cervical cytology

My findings reveal a range of individual and collective factors affecting South Asian women's access to cervical cytology. Although I will go on to show how racism and sexism affect access to screening, the following sections 5.3.4-5.4.2 examine women's personal beliefs and their effects on access. Firstly, I examine their attitudes toward cervical cytology and the reasons why women attend or do not attend for screening. I focus on their patterns of service use and on reasons why women attend regularly or irregularly. Secondly, I examine women's beliefs and views of cervical cancer and their knowledge of screening provision. The findings capture a range of personal beliefs, experiences and opinions.

5.3.4 Women's attitudes toward cervical cytology

As in chapter 4, the beliefs upon which health actions are taken are particularly important to an understanding of access to healthcare. A number of factors shape women's ideas and beliefs about why they should or should not use the service. Some of these ideas are mediated by 'race' and gender difference, others are rooted in a range of biographical and contextual factors that vary from individual to individual. I discuss the themes that arise from the data below.

The majority of those interviewed are generally positive about cervical cytology, its function, effectiveness and relevance to their own health. Nobody questions screening as a concept. Here they differ from many other South Asian women in other studies, for example, McAvoy and Raza's (1988) study in Leicester found that knowledge about, and

uptake of, cervical cytology among South Asian women was poor. My findings show a continuum of wider attitudes toward cervical cytology, both negative, positive and neutral, hence it is not possible to quantify each type. They challenge the pathologisation and homogenisation of minority ethnic women's health behaviours.

Many women feel that cervical cytology provision is a 'good idea'. This finding challenges the assumption that minority ethnic women are uninterested in preventative healthcare referred to in other studies (Bowes and Domokos, 1995a, 1993; Bradley and Friedman, 1993; Hoare *et al.*, 1992; Anon, 1991; Doyle, 1991; McAvoy, 1989; McAvoy and Raza, 1988; Baker *et al.*, 1984) and the notion that cultural taboos impose constraints on women's uptake of the test.

Some women hold more positive views about the test than others. They attend for screening in the belief that it is a 'good idea'. Their reasoning revolves around a 'need to know if they are healthy', to make sure that 'nothing is wrong', and to ensure early treatment should any problems occur. These ideas lead them toward rather than away from screening. The woman quoted below stresses the importance of cervical cytology to her health:

'Health checks. Yes they are good, you get, like they do smear test it's every three years I think, three to five years, yes that's good. Even though you can't be bothered like you don't like going for a smear test but end of the day it's good for you it's better to be safe than sorry you know. So yes it's...Good, I don't mind.'

'Like now HIV and things like that going on so it's good to have test [to see] if anything wrong with you. You never know anything could have happened, anything can happen with you so it's good if you can have a few test and you can find out these thing so why not? Even though some women they don't want to have smear tests but it's good for them...'

'Good is that it's good for you...I don't think there is anything bad.' [Indian woman age 27, 3501]

Some women are positive about cervical screening because it helps them to be positive about their health and to make sure nothing is wrong:

'It's important for me, it's good to know if everything is OK. If something's wrong with you you've got to get it treated isn't it? [Sikh woman age 42, 0903]

The accounts also suggest that cervical screening may convey feelings of safety and reassurance in health:

'It makes you feel safer, if anything wrong it will be detected earlier on.' [Pakistani woman age 33, 1402]

This type of thinking according to Posner (1993) illustrates that women's thinking is wider than medical thinking about the meaning of this intervention. Medical thinking emphasises looking for disease early on in order to increase successful intervention. For the woman quoted last, screening reassures her about her present and future state of health, that 'everything is all right', and that if a problem was to arise it would be caught in time.

Some women hold both positive and neutral views toward testing. They are positive about the test, want to know if they are healthy and want to ensure treatment, but their attitude toward testing also involves a degree of obligation to participate in the service:

'Good for us. That's why...for check-up no...They checks inside so if you've got anything wrong do something.

S.P.: Did you ask some questions during the test?

No. I thought the doctor knew better I just ask what for no?...They suggest me no?' [Indian woman age 59, 1504]

'...[S/he] says [GP] go for smear test so this is good for me. This is the way to find out a problem...' [Pakistani woman age 27, 3101]

'If the service is available and if it's good advantage for your health and it's good, good to know you are a healthy person I think a person should go and do that, you know. Because they don't have money to spend on unnecessary or unwisely. If there is something that's why they are spending that much money to do that care, so I am sure there is something, something logic behind it...'

She goes on to say:

'At least when there is something wrong with me I will know rather than [when] it's too late.' [Indian woman age 39, 0102]

Six of the other women hold more neutral views toward cervical cytology. These accounts also reflect an obligation to attend but they do not include ideas about the health benefits of screening like those of the women quoted above:

'To tell you the truth I don't know why it's important but the doctor tells me it's important.' [Pakistani woman age 35, 3402]

'INT.: I don't know really, I have no experience, whatever the doctors did to me, I feel like is good for me. Because I don't know why, good with me.' [Bangladeshi woman age 22, 2901]

The data suggest that women's neutral attitudes toward screening may affect their patterns of use of the service by compromising the regularity of screening. The woman quoted below has not been tested regularly because she has not been asked to attend:

'Well I think because it's important I think you should have it done because they say it's important. And I just go along with that.' [Sikh woman age 32, 0802]

Most of the women hold positive and/or neutral views toward screening. One possesses more negative views and is reluctant to attend. She recalls having her test done opportunistically in response to an inquiry by a medical professional. She describes how she avoids screening until she is 'caught', in her words, 'off guard'. In the interview she feels that screening is disgusting and thinks that it needs to be done during menstruation. For her, cervical cytology is a medical intervention that 'you have to have done', so that 'you have got to go'. This account suggests that where women feel that cervical cytology is not in their own control, their access is restricted. Feelings of a lack of control act to constrain the promotive aspects of screening described above.

'...obviously it's something that you have to have done.

S.P.: You have to have done?

Yes I think so.

S.P.: Why is it important to you?

It's not just important to me really. It's like obviously if there is something wrong and they can detect it, it is better to know than not know really. You know because then you can maybe get it fixed, the problem whatever it is...' [Pakistani woman age 23, 1301]

Attitudes toward cervical cytology are also located in women's wider beliefs about the difference between health and ill health. This is most evident in the accounts of four of the women who express feelings of the type 'if I think I am OK I wouldn't rush to have it done'. These women believe that they are not at risk from cervical cancer and feel they do not need to be screened because they are healthy or feel that nothing is wrong with their health. For them, the risk of cervical cancer and ill health is linked to the presence of tangible symptoms. The perception that women would choose to undergo cervical cytology 'only if there was a problem' is found in other studies focusing on other categories of women and cervical cytology (McKie, 1993; Gregory and McKie, 1992; Posner and Vessey, 1988; Elkind *et al.*, 1987; Eardley *et al.*, 1985).

‘But I wouldn’t rush to the doctor to get it unless I felt that there was something wrong, like in that department...If I feel I am OK then I think I am OK, that’s how I see it. But obviously there can still be things wrong with you, even if you feel all right.’ [Pakistani woman age 23, 1301]

The woman quoted below had her first experience of cervical cytology when she was almost 40 years old. She does not want to waste time using health services if she feels that there is nothing wrong:

‘If anything wrong with you, you feel like to go, you want to be something happening you know. But if you feel like you’re wrong, you feel like you’re wasting your time.’

S.P.: Do you have them regularly?

No really, I sometimes go, sometimes not, because I feel I’m all right, there’s no anything wrong with me.’ [Indian woman age 51, 0404]

The previous two quotations reveal a number of health beliefs and learned patterns of health service use. They reflect a perception that health services are used to cure health problems, rather than to keep healthy and a belief that health services should not be used ‘too often’, as seen in women’s attitudes to using the GP service (section 4.4.1).

The perception that women ‘would only choose to attend’ if there was something wrong [4 women], shows the ‘contradictory manner in which women are expected to interact with health services’ (Gregory and McKie, 1992: 82). As noted above, the concept of screening asks healthy women to present themselves, hopefully without symptoms. Traditionally, however, interaction with health services in general is based upon the presentation of symptoms to be diagnosed and treated. The accounts suggest that women’s perceptions about the role of health services in their daily lives and the learned strategies of health service interaction may affect their patterns of access to cervical cytology and may act to constrain overall uptake and the regularity of screening.

‘I know it is stupid but I feel healthy, I mean sometime you say you feel healthy and you have got something wrong with you and you don’t know until you get yourself checked, and if you don’t go and get it checked so often you don’t know and you feel OK. I like to say I don’t go to the doctor often, I go on and off whenever I...when it’s necessary so I feel healthy and I don’t...’ [Sikh woman age 23, 1901]

The attitudes of the women toward cervical cytology exhibit variation rather than cultural consistency. This study and that of Bowes and Domokos (1995a) provide no indication that South Asian women’s attitudes to cervical cytology are dictated by conventional ideas about South Asian culture. In general, the views of the women in my study do not differ

significantly from those of other categories of women revealed in other studies. For example, the majority of the women interviewed perceive that cervical cytology is diagnostic rather than preventative. They perceive that attending is a positive health behaviour because it enables women to find out about health problems and act on them, rather than to prevent cervical cancer. Ideas about cervical screening as a healthy behaviour, that is to keep healthy, are missing in many of the accounts.

Having looked at some of the reasons why South Asian women attend or do not attend for screening and shown that they are linked to ideas about the learned patterns of service use, the next section examines how women link their experiences of cervical cytology to other medical encounters.

5.3.5 Attitudes to cervical cytology: Links between the experience of cervical cytology and other health service experiences

Women's attitudes to cervical cytology are informed by other health service experiences. Thirteen women link their experiences of cervical cytology to other medical interventions, particularly their experiences of maternity services and internal examinations. This may be because many women had experienced screening as part of some other medical service (section 5.3.2). This section shows that the link between screening and other health services may affect subsequent screening experiences.

These aspects of the data challenge some accepted understandings about South Asian women and access to cervical cytology services. The literature draws on the link between cervical cytology and maternity services to explain South Asian women's poor uptake of cervical cytology. Anecdotal evidence, reported by Gregory and McKie (1990), suggests that South Asian women may not attend for cervical cytology because they perceive that screening is part of medical interventions during maternity care. It then follows that the regularity of screening is compromised and attendance is halted after childbearing ceases. I dispute this type of explanation because it focuses solely on the attributes of health service users and assumptions of their views, not on the attributes of health services or women's health service experiences.

In my study when the link between cervical cytology and other medical interventions is made, it allows women to make sense of their experiences of the service in two ways.

Firstly, the link allows them to express their experiences of the medicalisation of their bodies, where women are subjected to more medical interventions in health than men generally. Some women stress that they are 'used to this kind of thing' as they have experienced similar invasive procedures during pregnancy and childbirth. The accounts support a perception that cervical cytology is just another aspect of the medicalisation of life, where health professionals know what they are doing and know what is best for women. Secondly, the link allows women to make sense of the quality of their experiences of cervical cytology. Their experience of maternity care may mean that they learn not to question medical procedures, particularly those in the body spaces involved in reproduction. This means that women may learn not to question the way cervical cytology is offered to them, or to ask for help when they feel dissatisfied or confused or want to know more about what is happening to them (also see section 5.6.7).

These findings suggest that the way services are provided may affect the way women learn about the service and about the need for regular testing. They turn our attention to the way that services are offered to women and to the attributes of health services themselves.

5.4 Women's beliefs about cervical cytology

5.4.1 Beliefs about cervical cytology - what did the women think the test was for?

Access to health services is in part based on one's beliefs regarding the nature of an illness and perceptions of the likely outcome of medical interventions (Blaxter, 1985). I will argue below that access to cervical cytology also depends on one's position in society and on 'race' and gender difference (section 5.6). This section and section 5.4.2 examine women's beliefs about cervical cancer and about screening. In common with other studies of non-Asian women (e.g. Schwartz *et al.*, 1989), many women perceive cervical cytology to be a test *for cancer* and that the outcome of screening is a 'cancer - no cancer situation' (Gregory and McKie, 1991: 35). Few are aware of the role of the test in preventative medicine. The four cases quoted below are typical of the 16 who associate cervical cytology with the detection of cancer. All perceive that an abnormal result would signify that cancer had been detected:

‘S.P.: Would you know what an abnormal result would mean?

Yes I think you have cancer.’ [Pakistani woman age 48, 1803]

‘Something like I had cancer and was dying.’ [Bangladeshi woman age 26, 3701]

‘Well obviously it is cancer. It is cancer...I’ve heard that it can be treated quite successfully if it’s treated very early.’ [Sikh woman age 44, 0703]

The accounts reflect a widespread understanding that cervical cytology is curative rather than preventative, i.e. to detect cancer as a first step to treating it, rather than to prevent cancer (Gregory and McKie, 1992, 1990). The accounts reveal few ideas about the progression of the disease. No women volunteer that abnormal cells at early stages of invasive carcinoma are asymptomatic or that symptoms would signify that the disease was well established.

Thirty one women link the test to cancer. Nine name cervical cancer and another five name womb cancer, two associate it with cancer of the vagina, two to cancer of the uterus, and two women link it to breast cancer. Four women link cervical cytology to reproductive health. Eleven women link it to cancer generally. Ten women say that cervical cytology can diagnose more than one disease including infections of the reproductive system. One woman does not know what the test is for and many feel unsure in what they have said. Table 5.4 summarises what women think an abnormal result might signify. These are the views of women, most of whom have never had an abnormal result. Two women volunteer that they have received abnormal results, and that both were false positives

The significance of an abnormal result	No. of women
cancer is present	16
cells that might lead to cancer	2
might signify a false positive result	2
Don’t know - leave it to the health prof. to tell	4
Something is wrong/a disease/a problem	4
Don’t know	6

Table 5.4 What would an abnormal result mean?

The next section examines women’s wider attitudes to cancer and cervical cancer. This informs their beliefs about screening provision.

5.4.2 Beliefs about cervical cytology - A test for cancer

In discussing cervical screening, some women express their beliefs about cervical cancer and cancer more generally. Such beliefs are critical in controlling cancer (Johnson and Meischke, 1994) and add to an understanding of women's access to cervical cytology services. Although many women believe that cervical screening tests for cancer, this should not be seen as a reason for low uptake. A belief that women are tested for cancer may encourage rather than stop women from attending for screening.

Assumed barriers on uptake such as attitudes toward and the fear of cancer did not seem to deter attendance. This contrasts with other studies on cervical cytology which show that uptake is constrained by women's anxiety, apathy and fatalism about cancer (Naithoo, 1988), and that people's misconceptions about cancer make them delay obtaining medical treatment (Johnson and Meischke, 1994). Gregory and McKie's (1992) study of attenders and non-attenders and O'Donoghue's (1993) study of non-attenders both show that women may not want to be tested because they do not want to know of any problems that might be present. Older studies focusing on majority ethnic women's health behaviour also show that access to screening more generally, is constrained by the perception that 'one should not unnecessarily go looking for trouble' (Pill and Stott, 1988; Maclean *et al.*, 1984; French *et al.*, 1982).

Although it may be true that among women who do not attend, fear of knowing about health problems inhibits uptake, among those who do attend many identify similar fears as factors prompting them to take up the test. This is linked to women's uncertainty about health:

'...If you have a cancer or anything and you never know, you never go for a smear test that would be really bad...This type of illness always inside and you don't know what happens you must go for a check-up.' [Indian woman age 51, 0404]

Women's perceptions about the uncertainty of health enable rather than constrain access to cervical cytology. This occurs despite a heightened awareness of cancer issues (see below) and the diagnostic link to screening which acts to reinforce women's uncertainty. Three women feel that one can never be sure that 'one is fine' if diseases like cancer exist. This woman is relieved that screening provision exists as it allays her worries about the uncertainty of health:

'S.P.: Why is it [smear test] a relief can you tell me more about that?

Like you hear a lot about these things and you get worried, anybody can get anything and you don't know what's going on. And then if they check you and you're all right, that's fine, you know you are OK you know your body is fine, that's OK.'

'Hear a lot of things somebody's got womb cancer and somebody's not well and things like that and then the whole womb has got to come out, and you get worried [about hysterectomy]. I mean then the period finishes, and if the period finishes early life is not good for you...' [Sikh woman age 42, 0903].

'...They should get smear tests, I think all women should nowadays, because there's a lot of diseases about now and it's good that women should be checked...' [Sikh woman age 38, 1002]

'...if you have got cancer, you don't know if you have got cancer it appears to be cancer you can find it out from a smear test.' [Sikh woman age 23, 1901]

Twelve women talk about their beliefs about, and attitudes toward, cancer more generally. These ideas are bound up with the uncertainty of health and ideas about screening. Some women perceive the public to be more aware of, and better informed about, cancer than in the past. In contrast, one woman notes that cancer is something that is not discussed and identifies a lack of openness about cancer issues in her family and in wider society.

'So many this country no they are hearing television everybody die in cancer. If you don't want to check-up [have a smear test]. If tell earlier can go and do something you know. If you go later can't do anything no?' [Indian woman age 59, 1504]

'And cancer you hear on the telly is quite common now.' [Indian woman age 33, 2002]

Once again many women use the Indian subcontinent as a reference point to compare and contrast their healthcare experiences. This woman thinks that the public are better informed in the UK and compares the situation to India:

'Obviously it's a very frightening and dangerous disease...Like myself being born and brought up over here, I went to school and I was reading books...Watching television...the young understand a lot of them, even the younger ones that have come over from India like recently and that, they don't know nothing about these things.' [Sikh woman age 44, 0703]

Women's discussions of cancer and cervical cancer reflect a number of other perceptions that are illustrated in the quotations below. Firstly, they reflect a perception that cancer is no longer a death sentence and that medicine must be able to provide a cure and treatment for a condition. Secondly, they reflect a tendency to assume that if you are screened 'all will be well'. In this sense screening can offer a sense of reassurance to some women. The

accounts provide no indication that the women know of evidence that the risks of cervical cancer may be different for South Asian women compared to other women (Matheson *et al.*, 1985; Donaldson and Clayton, 1984). This finding is in common with other work on Pakistani women in Glasgow (Bowes and Domokos, 1995a).

‘...if you have got something wrong with you, they catch it in time and then they know. But if you don’t go for a smear test you don’t know what’s happening so...’ [Sikh woman age 38, 1002]

‘I think it’s important...because if someone had some minor problems and when it is in early stages...can be cured but if it develops then it’s very dangerous for the women.’ [Pakistani woman age 48, 1803]

This woman talks about the meaning of an abnormal result:

‘...there are two meanings to it. Sometimes there’s some disease and some *bemari* [illness] you can’t get better and there is some things you get better...’ [Pakistani woman age 35, 3402]

Most women perceive that there would be a positive outcome to any medical intervention should any problems be identified. The findings support a belief that early treatment usually makes a difference to the chances of survival. Thirteen women feel that any problems if caught early may be treated, (9 of these women feel that an abnormal result would signify the presence of cancer) and another eight women say that problems identified by screening may be treated. Seven women feel that they do not know.

Eleven women make sense of cancer by talking about their friends’ and relatives’ experiences. Significant others, that is particular individuals cited by women in their test experience, also affect women’s beliefs and attitudes to cervical cytology. The next section examines social support and access in more detail.

5.4.3 Social support and access to cervical cytology

Chapter 3 examined ideas about social support in the literature on minority ethnic groups and used the interview data to emphasise the importance of social support in women’s healthcare outside services. It is clear from my study that social support also plays an important part in women’s management of access to this service and affects women’s attitudes to, and uptake of, cervical cytology. Previous studies, however, pay little attention to the significance of social support in South Asian women’s access to cervical cytology.

One recent study by Gutteridge and Callaghan (1993), focusing on South Asian women and cervical cytology in General Practice, actually denies rather than investigates the significance of social support in accessing care. It concludes by asserting, without clear research based evidence, that South Asian women tend not to discuss health issues with each other or with family. It continues that it is unlikely that peer support and pressure will affect their access to and uptake of the service. My study challenges such anecdotal evidence. It shows that social support is important in this healthcare arena.

The value of social support is demonstrated initially in the interview data by women who report other women's experiences of the test whilst talking about their own experiences. Seven women describe how the screening experiences of their family and friends have acted as enablements on their own access. For example, four of these women reveal that they know someone who has had cancer or an abnormal smear. They show how others' experiences increase their own sense of urgency to attend. In addition, five women volunteer that they have been sources of health information about screening and support for other women.

On closer examination, the accounts show how women discriminate between who they talk to, and to what degree they confide in significant others. Most women feel that it is useful to talk to others, usually other women, about the test or if they are given an abnormal result. The interview data suggest that the women need to relate to someone properly, if they are to discuss their experiences of, or to ask questions about, cervical cytology. Issues of appropriateness and age appear to be important in the use of social support to enable access to screening. Ten women find it easier to talk to women of a similar age about such an intimate subject. Three women feel that they do not have enough of this type of non-professional support. Eight women feel that they would be inclined to use social support more if they were worried about screening or if they were to receive an abnormal result.

The role of social support in South Asian women's access to the service

Social support enables access to cervical cytology in a number of ways. Firstly, it helps women to learn about cervical cytology, especially about the need for testing, secondly, it helps to improve the quality of the screening experience for women, thirdly, it provides practical assistance to enable access. The study supports Gregory and McKie's (1990) work on cervical cytology and white working class women, which shows that reports of good

health service experiences from friends and relatives, for example, affect women's uptake of the service.

Chapters 3 and 4 demonstrated that women receive health information from a variety of channels. These aspects of the data show that social support helps women to learn about the service and about screening itself. Thirty one women describe how they have learned about cervical cytology and all identify the significance of social support. It should be remembered that this study can only comment on South Asian women who do attend for screening and that most of the women have had negative results. It may be that different channels are used should women's screening circumstances change, for example, after a positive result.

Aside from women's actual experience of cervical cytology, it is notable that women feel that they learn more about testing by word of mouth than from health promotion material such as leaflets and posters. Thirteen women emphasise the value of learning about cervical cytology in informal learning environments such as women's voluntary groups. The women are positive about the role of advocates, discussion groups and women's health sessions provided by the women's voluntary sector for South Asian women. The interview data suggest that linkworkers [2 women], friends and relatives [16 women] and women's voluntary groups [7 women] enhance the likelihood of attending and affect women's decisions to attend and to keep on attending. Only eight of the 35 women reveal that leaflets have helped them to learn about screening. Supplementary information is gained from other non-medical sources, such as the media, including television [8 women], women's magazines [2 women] and books [1 woman].

My findings mirror the conclusions of other studies on cervical cytology that stress the need to move beyond written and translated material for Asian non-attenders (McAvoy and Raza, 1991) and I would add for attenders, and beyond the use of traditional written material and sources such as TV and magazines, in relaying cancer information and health education campaigns. My findings also support other studies which show that women place a low priority on health promotion campaigns especially those based on leaflets (Gregory and McKie, 1990).

Social support also facilitates access to cervical cytology by improving the quality of the experience of the test. Significant others play a reassuring role. Eight women feel encouraged by friends and relatives who confirm that the test is 'good for you' and help

them to allay worries about the procedure. Significant others help women to think positively, to rationalise fears, for example, about positive results, and help them to 'talk out' their fears. The shared experiences between women also enable access to the service. Five women find it useful to talk to others if they have had similar experiences, for example, if the woman had found the test painful, has had an abnormal result, or has experienced the same language constraints in their experience of screening.

The interview data show that significant others play different practical roles to enable access to the service. Family and friends, especially other women, provide informal childcare and reciprocal caring in the management of access to the service. Also significant others remind women when a test is due [8 women], provide transport to use the service [2 women] and provide language assistance to harness this source of healthcare [5 women]. Two of the five women appreciate the help given by linkworkers from women's voluntary groups. These women debate the advantages and disadvantages of using others to assist with language. The findings are similar to my findings on access to the GP. Their concerns centre on: the ability of others to relay information to a health professional, the ability to co-ordinate with another person in their use of the service and on feelings of embarrassment at using a family member to discuss intimate subjects (section 4.6.5).

Five women stress the value of social support if women are new to testing or new to the NHS in the UK. The accounts of the two women below illustrate the importance of significant others to enable access to screening especially if one is new to the service and is reluctant to approach a health professional. These women stress the importance of knowing how the Health Service works. Their feeling is that access is easier for women who are UK born or have lived in the UK for some time. Both women have lived in the UK for less than 10 years:

'Every woman is not, you know...experienced unless [there is] somebody to tell her, [like a] mother or sister but I don't have here, mother and sister. So I just tell to my husband 'I did this, I feel this like that and go to doctor'. And you know sometimes we have a new doctor, sometimes not so I can't tell properly my problems [to the GP] because I don't want to [be] examine [examined by] doctor. I want lady doctor but sometimes [we] do [get a woman GP], sometimes not.' [Pakistani woman age 27, 3101]

'She [sister-in-law] told me everything, what they going to do because she been there first. She been here twenty years, more that twenty years so she knows everything. She told me you don't have to scare yourself and nobody give [will cause] you any harm.' [Indian woman age 32, 2202]

Following on from chapter 3, some accounts suggest that significant others act to fill gaps in screening provision. This is of particular importance in situations where women feel concerned about the approachability of health professionals. Adding to the findings in chapter 4, most of this concern is directed toward GPs.

Some women feel that it is easier to communicate with significant others than with health professionals. Their accounts reinforce the point that social support plays an important role in enabling access to screening by providing advice, 'genuine concern', understanding and emotional support:

'She [friend] really genuinely cares about me so she is giving me good advice. Whereas the others it's just like a job for them...But having that support, genuine concern, does make you feel you should do it [attend for screening] really.' [Pakistani woman age 33, 0303]

'It's easier talking to women because they are same, they know, like what is happening to them and what's happening to us like. But talking to a professional I don't think so...I don't think they understand anymore, I think you're better talking like to a woman, like my friend...' [Sikh woman age 38, 1002]

Chapter 3 showed that women stress the importance of health visitors in their own healthcare and are positive about their health promotion work. Some women identify the importance of health visitors in their experience of cervical cytology. The importance of health visitors to enable access is also seen in other studies on cervical cytology and South Asian women (Gutteridge and Callaghan, 1993) and on other categories of women (Campbell *et al.*, 1996; Elkind *et al.*, 1989).

This woman describes the disadvantages in learning about cervical cytology from friends. At the same time she feels that she is unable to approach her GP 'just to ask questions about cervical cytology'. She identifies the importance of her health visitor in her own healthcare and in providing information about screening:

'...health visitor I think she would obviously have more information than my friends probably would. We tend to sort of like talk and talk but sometimes we don't know the full information ourselves. I think the best information comes from her or the doctor...' [Pakistani woman age 23, 1301]

Another woman describes what she sees as the complementary roles of social support and professional help to enable access to the service. She reinforces the psychological role played by sources of non-professional support:

'Well talking to people it would help me in a way to relieve my stress. Talking to professionals is helping me professionally about a problem.' [Sikh woman age 37, 0202]

I conclude from these aspects of the data that social support plays an important role in women's access to the service, although, it is not the only factor prompting women to access cervical cytology. The data show that social support cannot take the place of health services in enabling access to screening.

Social support provided by partners/husbands

As noted above, women are discerning over who they talk to about screening and that there are limits to the use of social support to enable access to cervical cytology. Other studies and my findings in section 3.5.2 urge an examination of potential negative effects of significant others on women's attitudes to, and experience of, the service. One area of concern has been men's attitudes to cervical cytology. McKie (1995) and Gregory and McKie (1992) show the constraints posed by male attitudes on access to cervical cytology services. In particular, they show men's proprietorial attitudes toward women's bodies have an adverse effect on women's views of the test and contribute to women's reluctance to attend. They argue that this sense of ownership and control over women's bodies is linked to wider ideas about promiscuity, women's sexual lives and health and to ideas about the test itself (McKie, 1993; Gregory and McKie, 1992, 1991). In terms of my study, a sense of ownership and control over women also has a 'race' dimension. It is part of the cultural stereotype of South Asian women (Brah, 1992). I will now examine whether and how these ideas were expressed in the interviews.

All but one woman are married, 25 say they have talked to their partners about cervical cytology. Two women feel that it is unnecessary. In common with McKie's (1995) findings other men are not mentioned. Ten of these women say they speak to their partners after they have been tested or have received their result. Three women feel that they would use the support provided by partners more 'if there was something to worry about', for example, if they received a positive result.

Only three accounts seem to support ideas about proprietorship, one of the women is quoted below and another woman draws on the experience of another Bangladeshi woman. It is not possible to discern whether men's proprietorial attitudes affect test uptake for many women. Such attitudes did, however, compromise screening regularity for one woman. She describes her husband's dislike of male doctors undertaking gynaecological examinations:

'I think he [husband] was a wee bit put out you know. I said 'when I was having children I got a man doctor every morning, what did it bother you for?' He just thought oh...I knew his attitude would be like that...that's my property, nobody else should touch it...' [Indian woman age 33, 2002]

On balance then, and in contrast to studies by McKie (1995, 1993) and Gregory and McKie (1992, 1991), my findings suggest that for the majority of the women interviewed, the attitudes of husbands/partners act to enable rather than constrain the uptake of screening.

The form of social support given by partners differs compared to the support provided by gender networks of care, that is between women as described above. Social support given by partners/husbands enables access not so much by being involved directly in attendance, but by providing reassurance [4 women], by being positive and supporting perceptions like cervical cytology is 'a good idea', 'is good because the GP said so', or is 'good for health' [10 women]. Social support provided by partners also helps women to allay any anxieties that they may feel about their test results.

Practical support by partners to harness the service is also important. Three women mention assistance when going to the clinic, and one woman mentions language assistance. Three women also reveal that they value their partners helping them to learn about the test because their partners have been in the UK longer and are therefore more familiar with the way that the health service works, rather than the screening service more specifically. This woman has been in the UK for five years and her partner had been brought up in the UK:

'...I don't know many thing about smear test because I didn't know anything about them in India, so I didn't know anything and my husband knew so encouraged me, and I thought yes it's good for me.' [Indian woman age 27, 3501]

Two women feel that their partners have negative attitudes toward the test, though this does not appear to affect their uptake of the test. One woman feels that her partner questions its value, is dismissive, jokes about the need for testing and sees it as 'a waste of time'.

Fourteen women feel that men know little about cervical cytology. This occurs despite a feeling that partners are generally supportive about screening and a perception that people are better informed about cancer than they have been in the past. Other studies on majority ethnic women have found that women feel that men have little or no conception of women's health issues including cervical cytology (McKie, 1995). In my study, some think that men should be better informed. The two women quoted below are typical of the three women who feel that men do not want to know about, what they describe as, 'women's problems':

'I don't think some men bother too much about women's things you know.' [Sikh woman age 37, 0202]

'...I don't think men know very much about it. They should know. There should be more information for the men as well, because it's a serious matter if you do get it....They don't see women's problems...' [Sikh woman age 31, 0602]

This perception that cervical cytology is a 'women's problem' has implications for health education where the role of men in transmission of HPV or wart infection has been widely implicated in cancer causation (CRC, 1994). Clearly the rise in incidence of cervical cancer is more complicated than just a 'women's problem' and health education needs to involve men too (see also section 5.2.4 and appendix 4).

Social support and the views of others affect women's attitudes towards, uptake of and experience of cervical cytology. In women's perceptions of screening, social support assists with the social and psychological, informational and practical dimensions of attending. Social support is an unseen but positive part of the service (Gregory and McKie, 1990). It is used both overtly and covertly to relay information and provide support that is more immediate and personal than published health information for example. The interview data suggest that social support enhances attendance and the likelihood that women will keep on attending. The accounts suggest that it is effective in persuading, reinforcing and reminding women to adopt healthy behaviours and to use the service. The social and psychological dimensions of social support are particularly important and may act to fill gaps in service provision. However, the findings have also shown that social support cannot take the place of health service provision. In the main social support is viewed positively but it has been shown to have some limitations. I have illustrated this with respect to the support given by men, and that given by other women compared to health professionals.

The importance of social support holds a number of implications for provision. My findings support those of Gregory and McKie (1992, 1990) in indicating that significant others mediate access to the service and that social support is an unacknowledged resource which is turned to frequently by women. This means that good health service experiences and more time and attention given to each woman is a more effective promoter of this health service than other health education strategies such as leaflets or posters. Social support is important in the healthcare of most of the women interviewed. Its importance is reinforced by the findings of other studies which show that South Asian women are less likely to have

been screened in the past than non-Asian women (Bradley and Friedman, 1993; Doyle, 1991; Firdous and Bhopal, 1989; McAvoy and Raza, 1988).

5.5 Women's experience of cervical cytology - key issues and concerns

Despite positive attitudes toward cervical cytology, the women express concerns about the way they are treated, certain aspects of the procedure, screening organisation, and about the circumstances in which screening occurs. Many of the South Asian women's concerns are similar to those held by women from other ethnic backgrounds revealed in other studies. The sections below address: women's knowledge about the test; the prospect of the test; the system of organisation; the implications of the test and the efficiency of cervical cytology. The women's concerns move the debate about access to the service toward the attributes of the health services and away from the attributes of women. It is clear that women's concerns mediate access to cervical cytology in terms of subsequent uptake, attitudes to subsequent screening and the quality of screening experience. Many of their concerns are based in their past experience of cervical cytology which clearly affects future access to the service.

5.5.1 Knowledge of cervical cancer and cervical cytology services

Studies argue that lack of knowledge about the causes, prevention, detection and treatment of cancer is a significant problem confronting the control of cancer (Johnson and Meischke, 1994). They also argue that information mediates between women's perceptions of the threat of disease and their health actions, including attendance for screening and other risk minimising behaviours. Eardley *et al.* (1985), for example, argue that a prerequisite for the uptake of screening and regular attendance is an adequate level of knowledge about the service. In addition, Posner (1993) argues that information about screening, its risks and benefits and options after screening is ethically imperative if women are to give their informed consent to take part in the service. It is, important, therefore, that women are informed about this medical intervention. Sections 5.4.1 and 5.4.2 discussed women's ideas about the need for screening and their beliefs about cancer. This section discusses further issues in women's knowledge about the test and service provision.

Women's knowledge

The accounts show variation in the women's levels of knowledge about cervical cytology and cervical cancer. My findings support other studies which show that many women hold incorrect information about screening. These studies include those focusing on other categories of women (Gregory and McKie, 1992, 1991, 1990; Schwartz *et al.*, 1989; Posner and Vessey, 1988) and on South Asian women (Bradley and Friedman, 1993; Firdous and Bhopal, 1989; McAvoy and Raza, 1988).

Although all the women have some degree of knowledge of cervical cytology, it might be thought that low levels of knowledge of a service would be accompanied by low uptake. My study shows that women attend despite patchy knowledge and without understanding precisely what the test is for or its implications, whilst also holding on to the idea that screening is 'good for you'.

The accounts show that it is not that women do not want to know about cervical cytology or are uninterested in preventative medicine but that the majority of women want to know more about cervical cytology. Twelve women want to know more about the need for cervical cytology and about screening services and are willing to receive more information about healthcare. Twenty two women say that South Asian women in general need more information. Some are more specific about their information requirements. Eight want to know about the function of the test, seven want to know what happens after an abnormal result, two women want to know exactly what an abnormal result signifies. The need for information remains true even though women have had previous tests. According to Gregory and McKie (1992: 78) this suggests 'screening is taking place at the behest of health professionals with little concern for the awareness or knowledge demonstrated by women.' Some feel that they should know more about the way cervical cytology services are provided. The accounts show that some women feel they lack any choice in service provision. In particular, many women are unaware that cervical cytology is provided outside General Practice.

The women's accounts and their knowledge of cervical cytology also dispute the findings of other studies which have found that South Asian women possess less detailed knowledge about screening than non-Asian women (Firdous and Bhopal, 1989). The women are sure of the need for regular testing, though a minority of the women interviewed are seriously misinformed about the frequency with which screening needs to be done. Table 5.5 shows

that 11 of the 15 women who have attended regularly and six of the nine women who have not attended regularly, know that testing needs to be done every three years. This contrasts with other studies that have identified women's misapprehensions about the need for regular testing, including studies on majority ethnic women (Gregory and McKie, 1991; Posner and Vessey, 1988) and on South Asian women (McAvoy, 1989; McAvoy and Raza, 1988). These findings suggest that the views of South Asian women are in line with positive health behaviours. As noted above, policy and provision emphasises the regularity rather than frequency of screening (section 5.2.5).

Regularity of screening	15 Regular attenders	9 Non - Regular attenders	9 One test only
Every 3 yrs	11	6	6
Every 4 yrs			1
3/4 yrs	1		
2/3 yrs	1		
3/5 yrs	1		
1/2 yrs		1	
yearly		1	
Over the age of 50		1	
After birth of baby	1		
Don't know			2

NB one woman could not remember if she had had regular tests

Table 5.5 How often does screening need to be done?

It may be either that health professionals underestimate the amount of information patients want (Marteau, 1989b), do not have time to spend with patients, or that the information the women have been provided with and retained is limited to the regularity of screening and the idea that the test is to 'diagnose cancer'. Although seven women feel that either they or others might feel daunted by the responsibility of being informed fully about risk factors or the need for testing (Gregory and McKie, 1991), the majority of women in this study say they would prefer to have more facts. This, they say, would enable them to make informed choices, to feel positive about the nature of testing, and may even reduce anxiety about testing. I will illustrate this point using two accounts.

The first woman is not satisfied with the information she has been given. She is positive about screening, but given more information she would feel more relaxed about the test. Both her tests have been taken opportunistically:

‘...smear test or other test because I don’t [haven’t] been [through] these things before so I don’t know. If I go myself to see doctor for smear test I don’t know myself why is this. If somebody tell me first then I begin to relax myself. Other things, I don’t know what’s these things.’ [Indian woman age 32, 2202]

The second woman does not feel that she needs to know more about screening but stresses the value of being informed when she attends each time:

‘...you have knowledge of everything and when you know what is problem with you and what is this about then you feel much satisfied...if you have much knowledge of something you are content that you do this, and why this is happening and why they are doing this...’ [Pakistani woman age 48, 1803]

Giving information

Women’s concerns about knowledge are more complicated than simply knowing what the test is for and how often it should be done. My findings urge an understanding of how screening information is conveyed to women. They support those of Gregory and McKie (1992) which make the important link between women’s knowledge about cervical cytology and the circumstances in which screening occurs. In part, my findings agree that lack of knowledge may be a consequence of high levels of opportunistic screening.

The accounts stress the need for information to be communicated in appropriate ways. This woman has been screened more than three times but feels that she wants to know more about the need for screening:

‘...If somebody would explain to me little bit more in simple language rather than ‘doctor language’, because ‘doctor language’ they always use big words.’ [Indian woman age 39 0102]

‘I think Asian women are not told what it is all about or explained to them properly, if they were explained and understood quite well why is it important for you to have then I think they would go...if I knew more I would say definitely it would be good to have it.’ [Indian woman age 41, 2803]

The accounts also give ideas about good practice. The woman quoted below feels that she learned more from her time at a ‘women’s health day’ organised by the women’s voluntary group that she attends, than from other sources of information. Once again this reinforces the importance of informal channels of health information and gender networks of care. The woman feels that she was not given the opportunity to ask questions at her last test and adds that this would have made her feel more at ease:

‘S.P.: What would you like to know?’

The basics, what we sort of learned from the Q. [local] Health session. If there is things, where do you go, the clinics, the procedures after the test is positive. That's important, it sort of settles your mind if you know a bit more. Even the nurse would have helped if she had told these things, but she didn't.' [Sikh woman age 31, 0602]

Some also feel that they would like to be reminded of the need for screening at the time they are screened, even if they have had a test. Some of the women sense that they were given less information each time they attended but feel they need to be reminded.

The idea of a 'gold-standard' test was seen in the media around the time of interviewing in connection with a series of service related incidents (Lang, 1993) (see also section 5.5.4). I employed this idea in my questioning and aimed to gain women's views about how the service could be improved. A gold-standard test should involve a pre-test chat about a woman's state of health, periods, contraception methods and what the test is for. It should include provision to make the woman comfortable and allow her to be talked through the procedure during testing. The woman quoted below is typical of the 16 women who feel that such provision would be a good idea, seven other women had had, and another seven women say that they do not need, this facility.

'Well yes if you knew you were going, you would go more regular I would say than ignore it or you would be more eager to go if you knew more information.' [Indian woman age 41, 2803]

'I think it's best to know before what's going to happen to you or what you are going to take before.' [Bangladeshi woman age 27, 3701]

The findings and ideas about good practice have implications for health promotion where having a previous test has been found to be a significant factor in the uptake of subsequent tests (Pierce *et al.*, 1989; Eardley *et al.*, 1985). Of those women who feel that they do not need to know more about cervical cytology some say that they have good relationships with their GPs, and could easily approach them should they require more information.

Risk factors

Many women are unsure of the factors that have been shown to contribute to the development of cervical cancer. Factors such as smoking, the contraceptive pill, diet, fertility history and environmental factors like environmental pollution, occupation and partner's occupation are rarely voiced. Seven of the 35 women know that there are certain risk factors associated with cervical cancer. One woman talks about sexual transmission, two talk about the number of sexual partners, one cites vaginal infections, five women cite

smoking, two say drinking alcohol and one woman cites diet. The role of men in the development of abnormalities was seldom recognised.

There is a lack of awareness about the role of sexually transmitted disease in the incidence of cervical cancer. As in studies on majority ethnic women, many of the South Asian women are not aware of the HPV transmitted by male sexual partners (McKie, 1993; Gregory and McKie, 1992, 1991) which is widely implicated in the incidence of the disease. Whilst women's lack of knowledge is generally considered to be a constraint on access to cervical cytology, some studies see this particular gap in knowledge more positively (Gregory and McKie, 1992, 1991). They show that an emphasis on sexual transmission may discourage women from attending if they feel that they will be blamed should screening reveal any abnormalities (Gregory and McKie, 1992). It is clear that information on this issue is difficult to get right but the data indicate it would help women to keep informed about the need for screening.

Studies by McKie (1993) and Gregory and McKie (1992, 1990) show that some women link their attitudes to screening to sexual behaviour and associate promiscuity with a positive result. In my study, some of the women also make links between screening and sexual behaviour, however, this is perceived to affect women differently according to lifestage and has implications for women's knowledge about the test.

A number of studies acknowledge variations in the risk of cervical cancer for women born in different generations and show that they may be linked to changes in patterns of sexual activity (Murphy, Mant and Goldblatt, 1992; Murphy and Osmond, 1992). Studies do not, however, consider the wider consequences of generation or lifestage as perceived by women themselves and the effects of these factors on women's attitudes to screening.

My interview data suggest that certain women are perceived to have less knowledge and are less likely to be included in information flows about screening between women which, as has been suggested, enable access. This is closely linked to lifestage and to generation. The data suggest that unmarried women may not be told about screening by other women. Indeed three women volunteer that they have not talked to their unmarried non-sexually active grown-up daughters about the test. Some women, however, feel that second generation South Asian women are more informed than those women who have recently come to the UK from the Indian subcontinent.

These findings have implications for access to the service. They are significant as authors argue that screening programmes need to affect healthier lifestyles from the outset (Bowling, 1989) and, therefore, that younger women need to be told about the service and the risk factors associated with cervical cancer. In addition, constrained information flows may reinforce a perception that the problem of uptake of the service is an older women's issue and reinforce the lack of awareness about increasing rates of cervical cancer in women below 35 (section 5.2.4). Constrained information flows may also affect women's understanding about the role of men and HPV in the spread of cervical cancer. In terms of health education, as Gregory and McKie (1991) argue, these ideas cannot be addressed using conventional forms of information or treatment, but may be counteracted by services giving more accurate information and by sympathetic practice.

In discussing cervical screening three women identify lifestage as a risk factor and that older women are more at risk. No-one volunteers that younger women are a high risk group. This is significant given the true rise in incidence of cervical cancer in women under 35 (CRC, 1994). Also it is notable that only one woman volunteered that she wanted to know about ways to prevent or change her behaviour to reduce the risk of cervical cancer. This may be related to the widespread perception that cervical cytology is a test 'for' or a means of diagnosing cancer and that the outcome of screening is a 'cancer-no cancer' situation (Gregory and McKie, 1991: 35) rather than a form of preventative health behaviour within health services.

If screening is to be considered a healthy behaviour for women, the preventative nature of cervical cytology needs to be emphasised. This chapter has shown that screening blurs the boundary between healthcare outside services and inside health services in urging women to use health services when healthy (section 5.2.4). It has also indicated that cervical cytology screening is perceived primarily to diagnose cancer and also that the women have patchy knowledge about risk factors and risk minimising behaviours. These findings are significant as cervical abnormalities are associated with sexually transmitted disease. In the longer term such lack of understanding may undermine the wider, in particular, the promotive, benefits of using this preventative health service. It may also skew the management of cervical cancer toward health services and away from women's individual healthcare practices not involving service use. These findings suggest that improvements in the quality of information gained by the women may enable access to cervical cytology.

5.5.2 The prospect of the experience of the test

According to Eardley *et al.* (1985) a prerequisite for regular uptake is that women must find the prospect of the experience of the test and its implications accessible. Some women tell me that they find the prospect of the test relatively unpleasant. The interview data suggest that factors such as pain, discomfort, fear, embarrassment incurred by the screening procedure, constrain access and affect the quality of the screening experience and subsequent uptake. This is also seen in other studies on other categories of women (Campbell *et al.*, 1996; Gregory and McKie, 1992, 1991, 1990; Schwartz. *et al.*, 1989). Many women's negative perceptions are often rooted in past experiences of cervical screening:

'When I went to my doctor I was worried sick. I was five years overdue for that test because I kept putting it off because the last time I had it I was so hurt. It does hurt a bit when you have a smear test and I think that made me a bit scared you know. So I kept putting it off [even though] it's there for your benefit...

I remember how hurting it felt when I was having it done, I was more scared of the hurting.' [Bangladeshi women age 26, 3701]

'...I am one of these people where sometimes when I think it is something that is going to hurt then I won't make an appointment to get it done. And I will probably get a letter reminding me to have it done but I won't go for it. Whereas [last time] she [GP] caught me off guard, obviously it got done and I do remember that it was negative...' [Pakistani woman age 23, 1301]

The two cases quoted above show that women's negative experiences of screening and their concerns about the prospect of the experience of the test, can compromise the uptake and regularity of screening. The data suggest that women's negative experiences may affect access and that some women may delay their return date or be put off screening altogether. The first woman quoted above has had three tests but was five years overdue for her most recent test the other woman had one test and feels concerned about going for another.

The majority of the comments are about pain and discomfort [11 women]. Two women recall their experiences of bleeding during the test. The accounts point to the need for emotional support and comfort after screening. Some feel that they have to make allowances in their routines after being screened. For example, knowing that they are to attend and given their past experiences of pain during testing, two women find it necessary to allot time to recover. Two other women, including the woman quoted below, feel that

more attention should be paid to care after the test including provision to help women recover:

‘...I think they do enough when you are coming in but I think when you are coming out they think that’s it, they have done their job and that’s you...A smear test is quite a big thing for a woman...’ [Indian woman age 33, 2002]

The women express feelings of fear and embarrassment [9 women], shame or indignity incurred by the test procedure and process. Following on from section 5.5.1, two of the women link their fear to their lack of knowledge about the need for cervical cytology.

‘INT.: First of all she feel scared. She don’t know anything...she [the linkworker] gave me advice [the linkworker said] if I don’t do that it can be make harm and things, that’s why but I didn’t know anything [about the test]...

S.P.: Can you tell me a bit about what was scaring you?

The instrument.

INT.: That’s why she doesn’t go again.’ [Bangladeshi woman age 31, 2402]

‘INT.: ...I had no idea what I can expect. Because that time my baby is born and many times I have to go to the doctor, gave injection and this thing medicine, I think maybe it’s for me that’s why I feel very, when I scared, doctor want to do the test, that time I feel scared.’ [Bangladeshi woman age 28, 2501]

Others feel undignified and exposed and recount feelings of humiliation and powerlessness. This finding supports other work on Pakistani women (Bowes and Domokos, 1995a) and on white women (Gregory and McKie, 1992, 1991, 1990):

‘I was embarrassed it was worse than having the kids...When you’re having the kids you’re in pain so you don’t realise what’s going on. But when you’re having your test everything is OK and you know what’s going on. It’s more embarrassing than anything else...’ [Indian woman age 33, 2002]

For some, even the thought of the procedure can put women off the whole idea of screening and constrain women’s uptake and regular attendance. One woman feels uncomfortable with the procedure, her account includes feelings of humiliation and exposure whilst not knowing what will happen to her. She also finds the test uncomfortable. At the time of interview, she knew that her test was due but told me she was avoiding it. Another woman who has not had a test feels embarrassed about the intrusive nature of screening and because of this feels unable to attend.

5.5.3 The implications of the test

In common with other work on screening (Marteau, 1990, 1989a; Posner and Vessey, 1988) many women feel anxious when waiting for test results. This affects women's feelings about their experience of the test. According to Lang (1993) anxiety is one of the disadvantages of screening. Twenty of the women say they feel anxious to some degree about the implications of the test, though only two complain about the time taken to receive results or the manner in which results are given. The women express their fears about the possibility of cancer, gaining an abnormal result and about 'anything being wrong'. Even if health professionals try to reassure them at the time, some women do not feel finally reassured until they obtain their result. Five feel relieved when they get their results.

This woman has not been screened for six years and feels that she should attend:

'I am a little bit apprehensive, because so many women they are taking out these cells and it could be me as well...' [Sikh woman age 37, 0202]

Anxiety is also seen among regular attenders:

'Well there is always a worry at the back of your mind...because it can just happen you might have something, you don't know about...

This woman then talks about her results:

'...always a worry of just maybe the results might not be the way, not all the clear...as soon as you get an all clear I think you just forget about it...' [Sikh woman age 30, 1101]

Women's concerns about the implications of the test are linked to their feelings about the uncertainty of health:

'It's a relief anyway when everything is OK...Like you hear a lot about those things and you get worried, anybody can get anything and you don't know what's going on...Anybody can get...well like the cancer and things like that in the womb and nobody can see there really until they take the test...you know what I mean test it or things like that. As soon as you get it checked you're dying for your result to see everything is OK...' [Sikh woman age 42, 0903]

Five women reassure themselves that nothing is wrong whilst waiting for test results because they feel 'all right'. Whilst this attitude is widely seen as a constraint on uptake, and has been shown in women's attitudes to screening above (section 5.3.4), the accounts illustrate that it plays another more enabling role, helping women to allay fears about the implications of the test.

‘S.P.: Do you worry about getting the results?’

Not really because if there is nothing wrong with your body then I am sure there is nothing [to] worry about I am sure result will be OK. But if you are feeling uncomfortable if there is pain or something then worries.’ [Pakistani woman age 28, 2301]

This account reflects the common perception that ill health has tangible symptoms and may be linked to women’s lack of knowledge about cervical cancer described above (section 5.5.1). No woman volunteers the knowledge that the early stages of cervical cancer are asymptomatic.

Despite a feeling of reassurance incurred by the facility of screening described above, some women are concerned about subsequent treatment after a positive result, three women are concerned about the prospect of sterility. For example, this woman is positive about cervical cytology but fears the possibility of an abnormal result. She does not want to know much about follow up procedures because she fears the possibility of a hysterectomy. She talks about her fears by referring to the experience of her cousin:

‘...The last one [test result] came back, she [cousin] had cancer and then they had to cut out her womb, she couldn’t have any more children. I was worried the same thing was going to happen to me. I could hardly eat or sleep or rest for the first two weeks, because the doctor said it was [would take] two weeks for the test [her own] results to come back. When they [results] did come through the door it was such a relief.’ [Bangladeshi woman age 26, 3701]

5.5.4 The efficiency of the test

Seven women express concerns about the efficiency of the test. Three question the time interval between tests and feel that the test should be done every year to ensure early treatment at early stages of the disease. This response is linked to fears about cancer and the uncertainty of health. The case quoted below is typical in emphasising the frequency of screening:

‘...If they didn’t detect it and a month later you got something...for the next three years they won’t know if you’ve got it. That’s the main worry, not if you are going for it or if you have had it done or whatever. It’s those three years.’ [Sikh woman age 31, 0602]

Other concerns about the efficiency of the test are associated with media coverage around the time of the interview period in 1992 and 1993 which centred on problems with cervical cytology testing in England and Scotland. Reports focused not so much on the value of the

test, but on scare stories of tests being badly taken or misread and on variations in test standards. This type of incident and subsequent media coverage may cause anxiety and make women question health services in general and the efficiency of the test. For the women who talk about it, this does not, however, seem to dissuade uptake. Indeed for two women it increases the urgency of testing. Media reports around the time of interviewing cause more concern. No one mentions the withdrawal of cervical cytology services locally in Lothian after a number of misdiagnoses in the 1980s (Craig and Ineson, 1989). The three quotations below reflect women's uncertainty about health:

'Oh, things go wrong, the tests are wrong they weren't sure. I didn't worry about it. If you've got to go, you've got to go. What will happen tomorrow.' [Indian woman age 33, 1602]

'...You make sure they put your name on the bottle, I always do that I check. You get worried maybe you want to know, they're going to get mixed up or something. I do get worried about that.

S.P.: Why?

It's just like to know [the test is] your own. I know they wouldn't do that but when they write the name on the bottle or whatever they are going to put in you don't tell them you're looking at them, but you see your name's on it and that's it. Because sometimes I don't know, but sometimes I heard about somebody's wrong test or something...' [Sikh woman age 42, 0903]

'...What happened on the telly, what happened in Glasgow, like they were getting all the tests wrong...you don't want to be told you're negative when you're positive...If you're dying and thinking you are all right.' [Indian woman age 33, 2002]

5.5.5 The system of organisation

Other concerns revolve around the theme of the system of test organisation. The women interviewed hold strong ideas about how screening should be organised and how it could be made more acceptable. In line with my findings on access to the GP service (section 4.3.5), the twin themes of choice and continuity are important.

Access is affected by the health professional who takes the test. Twenty three women feel that they would prefer to be examined by women health professionals. As in chapter 4, gender preferences, rather than cultural or linguistic similarities or professional status, are important to the women. These are often expressed in association with a sense of embarrassment, shyness, modesty and dislike of being examined by male health

professionals. This finding is not exclusive to South Asian women, as studies on majority ethnic women show (Campbell *et al.*, 1996; McKie, 1995; Preston-Whyte *et al.*, 1983; Schwartz *et al.*, 1989), nor is it typical of all South Asian women, supporting the findings of other studies (Firdous and Bhopal, 1989; McAvoy and Raza 1988).

‘I would like a female doctor or nurse doing smear testing. I think I will go to E. [FPC] or some other clinic for it. That is one of the reasons why I avoid it because you know have to go to other GP which I usually avoid. That’s one thing I would like to change...Because it makes me feel more comfortable...in terms of physical examination.’ [Sikh woman age 37, 0202]

Supporting the findings in section 4.3.5, four women say that they feel better able to communicate with female health staff. Their accounts emphasise that good communication involves not only the ability to convey feelings and concerns to a health professional but also a feeling that health staff are receptive to the women’s concerns:

‘...It’s just you feel awkward there a few things you just can’t explain but you know how you feel about these things it’s just a little bit awkward you know I prefer going to a nurse.’ [Indian woman age 27, 3501]

‘they’re [female health staff] more understanding about the female body I think you become more conscious about the fact that it’s a man there.’ [Pakistani woman age 33, 1402]

The gender preferences of women when attending for screening underpin women’s negotiation of the service. Some of the women request a female GP before attending, whilst others express their relief that a trained nurse can take the sample.

‘I preferred the nurse...It’s more embarrassing really than anything else you know, but if there wasn’t a nurse there I’d probably have no choice.’ [Sikh woman age 32, 0802]

‘...It’s nice to get it done by a lady, isn’t it. It’s a bit embarrassing if he’s got to do it, or there is nobody there then he’ll have to, won’t you. Just to get yourself, just to understand it’s for your own sake and it’s OK. If not I would ask for a lady...’ [Sikh woman age 42, 0903]

Given the high number of women who would prefer women health professionals to take tests, it is notable that the majority of women do not seem to know about provision in Family Planning Clinics or well women clinics, where women are assured access to female health professionals. Fourteen women have been screened by a female nurse, usually a practice nurse and another three know that practice nurses can take smear tests. Eight women know about, and two women have had, tests at well women clinics. Nine women have had tests, and another four women know about provision, through Family Planning

Clinics. Two women mention health visitors and another mentions that midwives can take tests.

Continuity of care is also important. Seven of the 23 women who prefer a woman to take tests and six other women stress the continuity of care and the importance of a relationship with a health professional. Indeed most women say that they will return to the same service as their last test at their next screening time.

The women's concerns about continuity of care merge with physical dimensions of access to healthcare. The issue of proximity to screening services was expressed primarily in relation to GP surgeries. It is unsurprising that proximity to a service affects service use, however, the data also suggest that this affects women's familiarity with the service and their preferences about the screening service used. Issues of trust and familiarity also mesh with the women's confidence in the person performing the test as the following case shows:

'But if they offer me in the hospital which is far away which I don't know how to get to there or something like that I would probably make an appointment with my GP...At least I know my GP. And once you go in the hospital you don't know which doctor you are seeing you haven't met them before...It means a lot to the person because if you are going to the strange place, obviously if the travelling time is two hours there's no point...I think why go to the strange people if your GP can provide you all these things? Because you know your GP, your GP knows you.' [Indian woman age 39, 0102]

5.5.6 Attendance and non-attendance - the views of attenders

Although all but one of the women have been screened, the women were asked for their views about why some South Asian women might not attend for cervical cytology. The results are summarised in Table 5.6. This type of question was felt to be appropriate, as in many cases women drew on the experiences of others to reinforce their own experience. Indeed in the interviews, 13 women urge other South Asian women to attend. Whilst these views are not the views of non-attenders themselves, they increase the strength of my argument against the idea that constraints posed by notions of South Asian culture are a primary deterrent on access to cervical cytology services. They reinforce the point that unless reasons for non-attendance and women's experiences and perspectives are understood, the service will be misdirected (Bowling, 1989). The reasons given reflect the concerns of the women in this chapter. They are reinforced by this woman who has never undergone screening:

‘...Just feeling really uncomfortable about being looked at in that particular place you know...It’s just that I am very uncomfortable it’s so private...It’s really embarrassing...I think probably a lot of women do that’s why they don’t go. Even if they get sent information about it they probably don’t bother because they can’t read English. And they think because they can’t read English they don’t know how important it is in order to ask somebody else what it is...those who are married with children they wouldn’t feel uncomfortable...I don’t know how their husbands would feel... Also they probably don’t have enough knowledge either.’ [Pakistani woman age 33, 0302]

Factor Identified	no.*
Sense of intrusion on body spaces/embarrassment/shyness	16
Lack of knowledge	13
Fear of test and results	10
Lack of female health staff/not want male health professional.	9
Language constraints	6
Feel do not need to be screened	5
Constraints posed by links between screening and women’s sexual behaviour/promiscuity	3
Avoidance of problems/not want know if something wrong	3
Male attitudes to the test deter women	2
Gender role constraints	1
More familiarity with other ‘visible’ types of cancer in certain body areas e.g. the breast	1
Fatalism about disease	1

*= no. of women identifying factors as possible reasons constraining access to cervical cytology

Table 5.6 Factors that might affect South Asian women’s non-attendance for cervical cytology

This type of questioning leads seven women to identify differences in attendance at different life stages. They feel that non-attendance or irregular attendance, is more of an issue for older women and that age is a factor affecting women’s knowledge about the service and the need for testing. One woman, however, feels that irregular attendance is more of an issue for younger women and for first generation women who are new to the UK and unfamiliar with the health system. The findings about older women are important given that objective risks of cervical cancer are greater for this group. Other studies on majority ethnic women also show that women perceive older women to be at greater risk (Schwartz *et al.*, 1989). In my study, some women stress that one arm of the promotion of the service needs to target older women. Others volunteer that they have assisted older women to harness the service, and some of the Sikh women who have attended a women’s health session which included information about cervical cytology, say it was of value especially to older women. Generation and age affect ideas about attendance and ideas about improvements in service provision. This woman feels that more should be done to target older women. She highlights the importance of social support to enable access:

'From my experience there's not much information there for older women. We're younger, we can sort of gossip and get information. You get taught these kind of things at school anyway. You only get [information when] you are having a child in hospital whatever.' [Sikh woman age 31, 0602]

5.6 Collective factors and access to cervical cytology

The following sections examine the collective constraints and enablements on South Asian women's access to cervical cytology. They build on chapters 3 and 4 and show that access to cervical cytology is mediated by racism and sexism both outside and inside the service. In this healthcare arena ideas about muting are more apparent than in the other healthcare arenas. Sections 5.6.2 to 5.6.4 use the concept of muting to interpret women's experience of the service.

5.6.1 Gender dimensions of access to cervical cytology

Gender dimensions of access help us to understand both the experience and uptake of screening for the South Asian women interviewed. South Asian women do share certain experiences based on gender. I have already drawn attention to women's gender preferences of health professionals to take tests (section 5.5.5), and ideas about the medicalisation of women's bodies (section 5.3.5). Further ideas about gender difference and access to screening are examined below. I argue that gender role obligations affect how women use the service, why they use the service and their experience of service provision.

The women are concerned about their family commitments and the lack of childcare provision when using the service [6 women]. For example, they describe instances of waiting in clinics with small children in tow. Some describe how they negotiate their way around commitments to others, including their families, and around the structure of health services when they attend for screening.

Gender role obligations mediate the use of screening services. This woman shows how she negotiates demands on her time and the organisation of health services, and how both factors affect her use of the service. Her health needs are seen against the needs of others. She feels able legitimately to go for a test in what she calls her time, in this case when she is at work:

'...when I have to cancel something for my children I am not very happy. Then I have to find the time that doesn't disturb my children that doesn't disturb my husband, I work in between. As a working mother with a young family it is difficult to find time which is you know suitable for everyone. Sometime if the time is suitable for you it's not suitable for doctor.'

The negotiation around others and service provision is linked to physical dimensions of access:

'...If they offer me the same thing...in my working time and things like that, yes I'll go. But if they offer me in the hospital which is far away...then I'll probably cancel...'
[Indian woman age 39, 0102]

The accounts reflect the practical difficulties in access to the service shown in other studies focusing on majority ethnic women (Gregory and McKie, 1990; Pearson and Spencer, 1990; Pill and Stott, 1988). Against conventional understandings of South Asian women's access to the service 'perceptions of women's roles are intrinsic to the views and knowledge of the cervical smear test and services expressed by women' (Gregory and McKie, 1992: 80). In some cases, like the woman quoted above, gender dimensions mesh with physical dimensions of access. The effects of distance on access to the service may be associated with women's concerns about others, in particular their children.

Obligations attached to gender roles also mediate opportunities for screening. Another woman remembers her test which was taken opportunistically. Her account illustrates the effects of gender role constraints on service uptake by women especially those with young children. Her feeling is that she was able to have her one and only test because her children were not with her:

'Yes it was a lady doctor that did it. I remember I went in for something else and it was on the notes where it said I was supposed to have one and because I didn't have the kids with me that day for some reason, she said 'you might as well, you have got a bit of time, why not get it over and done with. It would save me having to come back again'

Well she mentioned once or twice that I was supposed to have one and I didn't actually make an appointment to have it done, and she caught me off guard.

S.P.: Caught off guard?

Well I went in for something else and she just said you have not done one and she said, I can't remember what she said but I just told her to go ahead and do it if it doesn't take too long and that...' [Pakistani woman age 23, 1301]

The interview data also reflect pressures on time resources which affect not only women's uptake but also their experience of cervical cytology services. Gender role constraints may

compromise the quality of the experience of screening by inhibiting the ability to learn about cervical cytology. The woman quoted above is one of two women who link their experience of opportunistic screening with their gender role obligations. Both feel that being 'put on the spot' in health services may 'interrupt' the effects of obligations attached to gender roles on access. Despite being criticised (section 5.3.2), opportunistic screening has a role in ensuring uptake of screening for some women.

Gender role obligations also affect how women feel about being screened. For two women this is linked to the perception that health is uncertain and to the implications of the test. This woman, quoted below, recalls her feelings about a suspected positive result. She perceives that the test is 'for cancer', i.e. to diagnose cancer, and considers the implications for her family including her school aged sons:

'I was worried like anything because my children were so small, if anything happens to me who's going to look after the children. Any time I get a little bit sick, I always worry about what's going to happen to my children.' [Pakistani woman age 35, 3402]

Gender role obligations affect the actual test experience. This woman recounts her difficulties in accessing the service with one nursery school age child, another primary school age child and her new baby:

'I go with my [children] and I says I don't want to this room in my daughter, I tell the doctor when you smear test. She says 'they are safe in the waiting room, they look after her if you don't want'. Because my husband is not with me and he can't come to [with] me and I have to do this smear test, I want to do this smear test but I don't want my daughter and the others to see.' [Pakistani woman age 27, 3101]

The woman quoted above stresses that she wants to be screened and the relevance of screening to her health. Instead of declining her test when attending the surgery with her three young children, she clearly negotiates the service and 'makes do' in a situation where there is little provision for those with children. It is easy to see how women may be distracted by their children and how this may mean they are unable to take in what the health professional is saying. Once again the environment in which screening occurs may be linked to women's ability to increase their knowledge about screening.

The accounts convey the effect of gender role constraints on access to the service at a number of levels, both in terms of going to the service and in women's experience of the service. They also show how constraints stemming from the obligations attached to gender roles may be reproduced in health services themselves, for example, where services do not

provide for women with young children. I have shown how gender role obligations and associated time pressures may detract from the quality of the test experience and affect patterns of use, including the regularity of uptake. The accounts show that women need the resources of time, transport and organisation to access health services. These resources are not available to all women (Pearson and Spencer, 1990) or to women all the time.

Physical dimensions of access mesh with gender dimensions of access. Mobility constraints and accessibility constraints, concerned with distance to services, operate within the wider limitations of obligations attached to gender roles by virtue of other commitments such as work or family. Where improvements in access to cervical cytology for women have concentrated on the health education of women (section 5.2.3), my study shows that improvements in access to screening need to address the logistics of the service provision.

Chapter 3 argued that maintaining health is important to the women, however, women's health behaviour is a negotiation of overarching demands on time resources and other commitments (Pearson and Spencer, 1990). Given the complexity of women's lives, it is easy to see how their own health may take a low priority in their responsibilities (Gregory and McKie, 1992, 1991; Pill and Stott, 1982). If screening is for the benefit of health and is provided for women, it is easy to see how women's health can be sidelined, put off or put back and how their access to the service may be constrained, especially in situations other than ill health. I have emphasised above how women may be blamed or seen as irresponsible if they do not attend (section 5.2.4). I conclude from these aspects of the data, that it is a mistake to label non-attending as irresponsible when it is considered in the context of time and space constraints on women's activity patterns and healthcare choices. The roles that women occupy mean that they are not just individuals who can act 'rationally' or 'freely' on their health beliefs. These findings on service use support those in chapter 3 which showed that women's own healthcare must be seen in the context of others and their needs.

5.6.2 The effects of muting on access to cervical cytology

As noted above, I will use Ardener's (1977) concept of muted groups to interpret women's experience of screening. Ardener (1977) is concerned with the domination of some voices by others, especially the domination of women's world views with men's world views. The muting process emphasises the role of speaking and the role of listening. Groups can be

muted if they are not listened to or understood and/or are unable to speak. This means that even if muted groups can express their own views they may continue to be muted in the dominant arena. Chapter 1 emphasised that the voices of minority ethnic women remain relatively unheard in health services, in policy and within the hearing range of dominant groups. In this sense muting is different from periods of silence in consultations which, it is argued, are a form of non-verbal communication and can play a positive role (Davidhizar and Giger, 1994).

The processes of muting are woven throughout the accounts which show how health services may contribute to the muting of South Asian women's voices, views, experiences and concerns. The experience of muting is not exclusive to South Asian women and may be experienced by other health service users. According to Ardener (1977) the processes of muting occur when a subordinate group interacts with a dominant order and Bowler (1993a) argues that the concept of muting can apply to all women using medical settings, if the dominant mode of expression is a medical one. The following sections examine the processes of muting that may be experienced by South Asian women in the same way as other categories of women (the gender dimensions of access), and where the processes of muting operate differently from other categories of women (the 'race' dimensions of access).

The processes of muting have been shown to operate in South Asian women's experience of maternity services (Bowes and Domokos, 1996; Bowler, 1993a). My study shows situations where muting affects access to a single primary and preventative health service. It also contributes to the debate by showing that muting occurs where women feel that they cannot ask health professionals for help (see below).

5.6.3 Muting and the gender dimensions of access to cervical cytology

Throughout, this chapter has argued that the attributes of health services not just the attributes of women affect South Asian women's access to cervical cytology. The interview data suggest health services play a role in muting women. Muting is induced by the nature of the screening procedure, and by the circumstances in which cervical cytology is given.

For some women learning about the test takes place in a health service environment where the processes of muting are dominant. Muting reduces opportunities for women to learn

about screening. It also constrains their ability to be active in their own healthcare. Women's lack of knowledge as described above, is one of the ways in which the quality of care is constrained.

Muting and the nature of the screening procedure

Two women feel unable to ask questions about cervical cytology given the intrusive nature of the procedure. In the interview this woman goes on to say that by the time the test was over she had forgotten what she wanted to ask:

'...Well I always have this thing like when the doctor says 'get up on the bed and take your trousers off and you know, lie down with your legs wide open' that's the uncomfortable part of thinking of it and then you think oh God what are they going to do now? And the actual test was a bit uncomfortable but it was over with, only a few minutes so I didn't think too much about it.' [Pakistani woman age 23, 1301]

Muting and the circumstances in which cervical cytology is given

Thirteen women first learned about cervical cytology as part of maternity care. As noted in section 5.3.5, the experience of maternity care may mean that women learn not to question medical procedures particularly those in certain body spaces involved in reproduction. This may mean then that women see medical interventions associated with reproduction ambivalently (Gregory and McKie, 1992). They may learn not to question the way cervical cytology is offered to them, or to ask for help when they feel dissatisfied or confused or want to know more about what is happening to them. They are in effect muted.

These three women are typical of the 13 women who first learned about cervical cytology in their experience of maternity care. All are enthusiastic about cervical cytology and its relevance to their health and all describe their first experience of testing at their six week check-up after the birth of a baby. One of the women recalls that her experience led her to delay subsequent tests. Another woman recalls the difficulties in learning about screening after having a baby. She feels now that she was not in a position to question or learn about any medical interventions. These aspects of the interview data suggest that, in such circumstances, the test becomes a procedure rather than an entitlement to keep healthy:

'How often I used to get them? I really couldn't tell you but for the last 10 years now I get them every three years. I know that I got a letter to the house because my kids are all grown up. Maybe they used to do them after six weeks check-up, after the babies and things like that. You are so busy you don't ask, you never got the chance to ask these questions from your doctor. Why you are doing this? Why are you doing that? And

what is happening? The result used to be fine and you were happy, but now you ask your nurse and doctors. Now I did ask smear test and that they told me.

S.P.: Why is it different now?

Now maybe I got more time, the kids have grown up, you are worried you want to know what's going on in yourself. Maybe earlier on you were so busy...Now you want to know...' [Sikh woman age 42, 0903]

This woman makes sense of her feelings by linking her experience of health services to her level of knowledge of cervical cytology. Health service experiences like these do not allow women to counter the circle of muting where women feel that they do not know enough about the test and at the same time feel that they cannot ask about it.

The following woman also says that she felt ill prepared due to the test circumstances. She blames herself for her lack of knowledge. This woman was told about the need for screening whilst in hospital after the birth of her baby. Both women feel that in other circumstances they would be able to talk to a health professional about screening:

'...I think because I didn't pay much attention to it, like I said I thought it [the test] was an x-ray thing you know, because I'd just had her [daughter] I was in stitches the doctor was explaining to me on my hospital bed and I didn't take much notice of him. I know he was saying things but in one ear out the other as they say. Well you know if I did listen to him I would be prepared for what was coming.' [Bangladeshi woman age 27, 3701]

As argued above, the circumstances of screening are linked to women's ability to learn about the benefits of and choices in undertaking cervical cytology. This leads one woman to differentiate between what she calls 'proper' and other cervical screening episodes that she feels had probably taken place after the birth of her children, thirty years previously. Another woman talks more generally about the circumstances of the test:

'...I mean obviously a lot of them got it done automatically after they had had their children and that, but I don't think they ever asked questions about what it was for or why.'

'And they didn't know it was a smear test they were getting, or that there was a special smear test that they should have been getting...'

She talks about the experience of her mother-in-law:

'...because she didn't know about it so there was no point in saying that she wanted it done because she didn't know about it.' [Sikh woman age 44, 0703]

The interview data suggest that access to the service and the quality of women's screening experience may be constrained if women feel inhibited and unable to become active participants in their own healthcare. The women quoted in this section show that constraints on access to cervical cytology stem from the attributes of health services. They show how women can become muted by health services where muting has more to do with the environment and intrusive nature of the test, the procedure and circumstances in which information about screening is given, rather than any constraints on access stemming from constructions of South Asian culture. These factors have a number of implications for access. Firstly, medical environments and the messages that women receive from them, can reproduce confusion, fear, dislike and all the other concerns of the women described above. Secondly, in such circumstances women's knowledge about screening may be constrained. Thirdly, if medical environments constrain women's ability to make healthcare choices and reinforce feelings of compliance with health services, a further implication is that the service may remain 'medically managed' rather than 'women centred' and the wider promotive healthcare benefits are thereby constrained.

Gender dimensions operate powerfully in access to cervical cytology for South Asian women. Interwoven with gender dimensions and the processes of muting are 'race' dimensions of access. The effects of ideas about 'race' difference on access to healthcare are specific to members of racialised groups in society (Miles, 1989).

5.6.4 Muting and the 'race' dimensions of access to cervical cytology

The interview data suggest that muting also works through ideas about 'race' difference. The women's accounts show that racism is a significant and persistent force in shaping their experiences in this healthcare arena. It acts subtly to make cervical cytology services less accessible to South Asian women.

In common with the previous empirical chapters, racism is a sensitive and difficult subject to discuss (3.6.2 and 4.6.3). The women wanted to be sure that what they identified was unequal treatment on the basis of 'race' difference, as the woman quoted below shows. Many of the women's experiences were not necessarily recognised as racist:

'...if it was a see-through window you could see...the way the English people are treated and compare yourself...' [Pakistani woman age 33, 1402]

5.6.5 Racism and access to cervical cytology - the interpersonal level

Some women link their experiences of 'race' difference to the attitudes of health professionals, however, more women refer to institutional [19 women] rather than interpersonal [5 women] racism. They refer to their own experiences and extend them to other South Asian women. The two cases quoted below indicate how health professionals may reflect beliefs held, and assumptions, about South Asian women and their health behaviour in the wider society. The first woman recalls how stereotyping shaped her experience of screening. She then questions the cultural stereotype:

'Yes she [nurse] said like 'some Asian women like they don't like getting it done, this smear test and then even they don't like getting, they bring their husband along with them'...so she was very surprised with me like I was so free about these things...and when she is doing it they [South Asian women] are being sissy, oh it's hurting when it's not hurting them. So she was very happy with me...It depends on person to person...like way of thinking...' [Indian woman age 27, 3501]

Her account indicates that the practice nurse in effect makes her feel different from other women because she is South Asian. Stereotyping stops the woman from playing an active part in her screening experience and contributes to her muting. After two tests she tells me that she still wants to understand the precise need for screening.

Assumptions about the health behaviour and culture of South Asian women may shape women's experiences of, and their responses to, screening. As noted in section 1.4.1, one of the effects of stereotyping is to mask sensitivity to the individual and her needs and wishes. In common with the women's GP experiences, stereotyping is a way in which discrimination based on 'race' occurs without the actions involved appearing, at least on the surface, to be racist.

Women may find it difficult to express their concerns about screening to health professionals, more so if their health behaviour is seen through stereotypes. The second woman's account reflects the processes of muting in a health service environment. She feels unable to approach health professionals or to ask about what is happening to her because she does not want to appear in her words, stupid. She is particularly confused and wonders if the test is 'for breast cancer'. She extends her experience to other South Asian women, seen in her expression 'our women'.

'...I think our women tend maybe not to ask too many questions, they just let the doctor do what he has to do sort of like you know. They just see it as a thing that has to be done

but they don't ask too many details about it. It's like you feel embarrassed to ask something. You shouldn't feel embarrassed obviously. If you can't talk to a female doctor then who can you talk to really?...

I don't mean that they don't actually go for the test. The problem is that they don't know too much about it and that they don't ask much about it. Probably they have got a male doctor or they feel embarrassed asking questions or they felt they should know already about it. They feel that *they can't ask because people think they are stupid...* I feel as though I should know about it and I feel that I should know. I feel as though saying, I think it is for breast cancer, I feel as though I have probably said the wrong thing.' [Pakistani woman age 23, 1301] [own emphasis]

These aspects of the interview data suggest that the processes of muting affect women's experience of, and subsequent use of, the service. The woman quoted above describes her only screening experience, three years previously and is concerned about subsequent tests. She volunteers that she had not responded to the letters sent to her by her GP both for her first test (she was tested opportunistically), or for her next test that was due at the time of the interview.

As noted in chapter 4, communication difficulties are part of the construction of negative stereotype and typification of South Asian women in their use of health services (Bowler, 1993a). This means that language constraints are assumed and attached to all South Asian women as a catch-all explanation for constraints in access to healthcare provision. The two accounts in this section suggest that women may be disadvantaged by assumptions about and stereotypes of the health behaviour of South Asian women (Bowler, 1993a, 1993b; Parsons *et al.*, 1993). These findings add to those in chapter 4. Whilst not wishing to deny the issue of language, the last quotation shows that communication issues in health service interactions are much broader for South Asian women than first thought. The woman quoted last spoke fluent English and had been brought up and educated in England since the age of three.

5.6.6 Racism and access to cervical cytology - the institutional level

Some women recount their experiences of institutional racism in cervical cytology services. As noted in chapter 1, institutional racism means that health service practices effectively exclude South Asian women and deny them access to health resources. The accounts show how the quality of care can be compromised and access constrained if women are muted by others who do not listen or do not ask. The interview data suggest that in health services there may be little incentive for the muted group to speak.

Access to healthcare is problematic for those with little or no command of English language. Although for some women this is not perceived as such, I have argued in chapter 4 that a lack of translation facilities/advocates reflects institutional racism (see section 4.6.5). Although the majority of women cite language as a factor in access to, and the use of, health services, what follows relates solely to women's experience of cervical cytology. Language problems affect 12 women's experience of testing. Some women blame themselves that their English is not good enough, and another seven feel that language is a central issue in access to the service for South Asian women.

Communication difficulties affect women's health service choices and their ability to define needs, to learn about healthcare, and to understand screening procedures. They also affect women's confidence in service use, and the ability to fit into the service. Communication difficulties can leave women confused and stop them asking for help. The women quoted below have experienced language problems in their use of the service:

'Yes but I think I have got an advantage with communication, I think that way. You can say what you want to say and how you want to say it...' [Indian woman age 33, 2002]

'...Plus main language barrier...I can say 'I want lady doctor I want this and that'...that is putting them off to have a smear test.' [Indian woman age 39, 0102]

This woman reflects on her past feelings about language problems. She links this to the ease of accessing the service:

'...other women they have their own language, they are in their own country and I think that makes it easy for them to approach for anything...If you can't speak very good English then you worry about doing anything you want to do, you feel you are not happy, your inside is not happy, you don't have the confidence that other women would have I would say...Because you are coloured you are not the same as they are and if you don't fit in their groups they are not going to accept you and that is very important to be accepted by a forei[gn]er...and you're different and if you start being different then it's so difficult to get into I would say.' [Indian woman age 41, 2803]

As noted in chapter 4, failure to recognise and allocate resources for language difficulties means that services do not provide for all women in the same way or to the same standard. This means that the experience of health services may be qualitatively different for some South Asian women compared to other users and that services are not truly ethnically sensitive.

To attend for screening one must possess an understanding of how the health system operates. Eleven women feel that other categories of women have better access to the

service because they speak the 'language of services'- they know where to go, and who to see at the outset.

This woman was introduced to cervical cytology and had been screened on registering at her GP surgery. She had been in the UK for only a few weeks and had limited fluency in English. She had not grown up in the context of a medical system where cervical cytology is part of mainstream care. Her experience led to feelings of anxiety and distress because she did not fully understand what was going on and was not familiar with screening or the health system. On returning home she told her husband:

'If that's what they do here, I want to go back to Pakistan!' [Pakistani woman age 30, 0501].

Another woman talks about her language problems. She depends on her school aged children to help her in daily life. On occasion she is able to use a linkworker, available through the women's voluntary sector, to assist her. She recounts her last test experience very angrily:

INT.: Now is little bit easier because they write the letter to go there to the clinic and nurse and check and they did not ask anything, they didn't make any question or anything just...

S.P.: When Mrs K. went they said nothing?

INT.: Yes...Then report they send by post.' [Bangladeshi woman age 31, 2402]

She feels unsure of the precise benefits of cervical cytology. There is no motivation to take the trouble to ensure that she understands the process or the nature and implications of the examination. Her experience of screening does not allow her to improve her knowledge, to attend actively for screening or to make a considered decision to attend because the health staff make no effort to communicate with her. In such circumstances cervical cytology becomes a procedure rather than a healthy behaviour. The informational and emotional dimensions of access, outlined above, are notably absent. This woman shows how her experience of screening contributed to her confusion. Even though a female health professional takes the test, as she wants, her interaction with the service is faceless and negative. Her views and feelings about the test are muted and she is offered no reassurance. The accounts show that for women with language problems there may be little incentive to speak. This woman is passive and quiet in her interaction with the service and complies with it.

If cervical cytology emphasises the wider health benefits of screening, this account shows how taking responsibility for one's health through the use of health services is constrained by the attributes of health services and the attitudes of health professionals themselves. In the case of the women quoted above, the benefits are not made clear and, from this perspective, screening may have caused harm. Tindall (1994) and Posner (1993) argue that to be ethically justified screening must offer clear benefit to the individual. The interview data suggest that women are not as aware of the benefits of screening as they might be and that this may contribute to feelings of confusion and fear.

The accounts suggest that lack of information is perpetuated by the system, not via the operation of a cultural taboo. It is not that health messages and benefits are not heard or fall on 'deaf ears' on account of South Asian culture, but that health messages may not be conveyed by health professionals to users appropriately or at all. According to Eardley *et al.* (1985) reasonable knowledge about preventative health and the value of screening is needed in order that women undergo screening regularly. In my study, access is constrained by inappropriate, or lack of, information where women become muted.

In conclusion, poor access to healthcare through the operation of racism, can be reproduced and reinforced by the actions of health services and health professionals. Health services and health professionals play a role in defining groups as 'different' and in making women aware of their marginality and making them feel different. At the same time, health services are ostensibly blind to the presence of different groups. For example, failure to provide for communication needs can create and maintain barriers on access to health services. One of the main damaging effects is that the actions of health services and professionals can reinforce the stereotyped view that South Asian women are uninterested in preventative healthcare. It follows that women can be blamed for their health service experiences and are seen as a danger to their own health. The pathologisation of South Asian women's health behaviours is thus reproduced.

Overt and covert racism operates both inside and outside health services. Some health service practices may have racist effects and reflect processes of racism by omission. Such practices alter the access of this category of women to appropriate services (Bowes and Domokos, 1995a). So called special needs, such as language assistance to enable the rightful access of South Asian women to this mainstream healthcare entitlement, may derive from culture, but non-response and staff attitudes to it are related to the attributes and

culture of health services (Bowes and Domokos, 1995a). In the process women are muted and may receive messages that they are ‘second class citizens’ who are perceived to be of low status stemming from their ethnicity. In mainstream service provision this means that the needs of South Asian women are left unmet and are not a priority.

I conclude that where women express the desire to be treated differently from other health service users, for example, they express the need for special provision, cervical cytology sessions just for South Asian women, linkworkers in women’s homes, language support, or to have a test done at home, this may be a reaction to being discriminated against, judged and made to feel ‘they think we are stupid’ or patronised in a number of subtle ways. Their choices are in many ways stimulated by racism rather than by cultural preference (Bowes and Domokos, 1995a). Table 5.7 summarises the findings on women’s suggestions for improvements to the service.

Way of enabling access	No. women
Advocates in services	8
Asian woman visiting women at home - esp. someone with social standing in community	4
Asian Health visitors at home	1
Through the voluntary sector e.g. health groups	11
Leaflets in Asian languages	2
Video on screening	1
Special facilities for Asian women	1

Table 5.7 Suggested ways of providing support to enable access to cervical cytology for South Asian women

It is notable that the women mention help in mainstream care rather than separate provision. They emphasise the value of social support to enable access to the service in appropriate ways. Once again, these findings support my argument for the use of advocates to enable service provision (section 4.6.5).

Ideas about ‘race’ difference compound the effects of ideas about gender difference in restricting access to healthcare. This means that South Asian women, as a racialised group, experience pressures and constraints in addition to those experienced by majority ethnic women. For example, if racism increases the processes of muting, then muting is experienced to a different degree by racialised groups. Bowler’s (1993a, 1993b: 171) work on maternity services argues that in medical settings and in a dominant medical culture, ‘minority ethnic women will be doubly muted because they are dealing with two degrees of dominance, white British and male medical.’ In addition, other studies on maternity care

focus on communication issues to explain inequalities in minority ethnic groups' health service experiences (Bowler, 1993a, 1993b; Homans and Satow, 1982). They show that South Asian women may be seen by health staff as difficult to work with and that health staff may be unable to have 'proper' relationships with women who cannot speak English fluently. They cite instances where stereotypical beliefs about minority ethnic patients, such as 'making a fuss about nothing', may limit the health professionals' willingness to communicate with patients (Homans and Satow, 1982). My study shows that issues such as communication, stereotypical health behaviours and a dominant medical culture, can be extended to South Asian women's experience of cervical cytology services. Some women clearly feel that health professionals limit their willingness to communicate effectively with them, if at all. Constraints on communication compromise the quality of the experience of the test for all women, *not* just those with language problems.

5.7 Conclusion

This chapter has emphasised that explanations of access to cervical cytology should not be confined to women's knowledge about screening, service uptake and the attributes of women. These factors are commonly emphasised in other studies on cervical cytology. My work suggests that conceptualisations of access should include women's experiences of, and perspectives on, cervical cytology services. This view has enabled me to show a range of other factors which affect access to the service among the South Asian women interviewed. Many of these factors are not quantifiable or are unseen and many are not normally flagged in explanations of access to cervical cytology for South Asian women. They include social support, the gender dimensions of access, women's attitudes toward cancer, cervical cancer women's positive preventative health behaviours and lifestage.

The findings in this chapter build on the two previous empirical chapters and have challenged conventional explanations of South Asian women's access to cervical cytology. Firstly, like the previous empirical chapters they have challenged explanations of access that have centred on conventional understandings of South Asian culture. The widely held assumptions that South Asian culture generates constraints which deter South Asian women from attending, and that South Asian women have little enthusiasm for preventative services, lack knowledge about screening and experience constraints on access to the service stemming from cultural taboos, are not supported by my findings. Secondly, my findings

have shown that the women do not hold beliefs about cervical cytology that may be called distinctively South Asian, Pakistani, Bangladeshi, Indian or Sikh.

The data, however, identify several factors which enhance women's access to the service. The women were enthusiastic about the idea of cervical cytology, none were vehemently opposed to it and only few women were embarrassed to speak to me about their perspectives and experiences. On women's uptake of and knowledge about screening, I have argued that the health behaviours of the South Asian women interviewed, in relation to screening, must be interpreted positively in the wider context of current health education messages and preventative healthcare provision. All but two women had had one or more tests, the majority of the women had had their first test between the ages of twenty and thirty and many women knew that screening had to be done regularly. This is in line with screening policy which emphasises the regularity rather than the frequency of screening and in line with the systematic screening and uptake rates recorded for other categories of women (Schwartz *et al.*, 1989).

Following on from chapters 3 and 4 it is apparent that access to cervical cytology is enabled by social support. Social support has been shown to affect women's attitudes to, and uptake of, the service and to enhance the likelihood of attendance. It plays a number of roles enabling access to the service by providing information and practical support. I have also suggested that social support acts to fill gaps in service provision, especially the social and emotional aspects of women's experience of screening. These findings dispute the anecdotal evidence in other studies which has dismissed the importance of social support in South Asian women's access to the service (Gutteridge and Callaghan, 1993).

The study has also identified a number of constraints on access to cervical cytology. At the collective level I have shown that access is mediated by ideas about 'race' and gender difference which run right through women's decisions to attend, their attitudes toward screening and women's experience of the service. As in the previous chapter, the women negotiate collective constraints on access so that they are not rendered passive in their experience of the service. A range of factors constraining access for the South Asian women interviewed are also shared by other categories of women identified in other studies. These have included beliefs about the nature of screening and cervical cancer, women's preferences that female health professionals take the tests, the medicalisation of women's bodies and constraints on the use and experience of the service posed by the obligations

attached to gender roles. Several factors affecting access to the service are specific to members of racialised groups. Stereotyping South Asian women's health behaviours in relation to the service and institutional racism detract from the quality of women's experience of screening and make women inactive in their own healthcare.

Access is also constrained by the processes of muting. Ideas about 'race' and gender difference have been shown to contribute to the processes of muting in South Asian women's experience of the service. The analysis has shown that muting may prevent South Asian women from expressing their fears and concerns and may mean that they are unable to speak and make their needs known. Muting may also distance women from being active in their own healthcare and affect their compliance with the service. Although muting may also affect other categories of women, it is apparent that the negative effects of muting are increased by the effects of racism. These findings add to those in chapter 4 which highlighted the issue of communication in women's access to the GP service.

Finally, the practices of health professionals and the attributes of services are included among the constraints on access to the service. Screening presents a number of access difficulties, including the system of organisation, communication with health professionals, and constraints on women's opportunities to increase their levels of knowledge about screening. I have also questioned the promotive aspects of the service and the opportunities that women have to attend actively for screening. Importantly, the accounts have revealed ways in which the assumed health behaviours of South Asian women persist. My findings have shown that the manner in which health services are provided can help to reproduce and support the negative social constructions of South Asian women, help to define South Asian women as 'different' and emphasise their assumed pathological health behaviours. This was demonstrated: firstly, where women's opportunities for learning about screening are constrained by health service environments, the nature of the procedure, the environment in which the test is given and by institutional racism and stereotyping; secondly, where the needs of South Asian women are overlooked; thirdly, where the processes of muting perpetuate misinformation and partial misunderstandings about cervical cytology; and finally, where health services do not provide to enable access to the service for South Asian women. All these factors act to constrain uptake and the quality of the screening experience for South Asian women. The findings have strongly suggested that health service practices and health professionals may help to support the assumption that South Asian women do not attend for cervical cytology and that they are not interested in preventative medicine.

The findings in this healthcare arena together with those reported in earlier chapters contribute to an understanding of access to healthcare among South Asian women more generally. This is the subject of my final chapter.

Conclusion

6.1 Introduction

This study has been concerned with the issue of access to healthcare for women of South Asian heritage living in Edinburgh. The findings contribute to a number of debates in minority ethnic groups' health studies, women's health and qualitative methodology, as well as to the growing field of medical geography. Chapter 1 presented a critical review of previous research and identified gaps in research, theoretical analysis and policy. In the light of these debates it set out my research frame and justified a focus on access to the three chosen healthcare arenas: healthcare outside services, the GP service and cervical cytology services. Chapter 2 justified and outlined the methodological approaches taken, presented an account of the implementation of these approaches and examined a number of debates about interviewing and data analysis. Chapters 3 to 5 presented and analysed my empirical findings and highlighted a range of enablements and constraints on South Asian women's access to healthcare in each healthcare arena. In this chapter I will draw seven substantive conclusions from my study, make a number of suggestions for further research work and outline the policy implications of my findings.

6.2 Substantive conclusions

My study and the views expressed within it have raised a wide variety of issues. In the light of my findings and previous research, I have selected what I feel to be the seven main substantive conclusions. These link the findings from each healthcare arena and inform debates on access to healthcare, women's health and minority ethnic groups and health.

My **first conclusion** is that user views are central to an analytical understanding of access to healthcare for South Asian women. Throughout this thesis I have argued for a broad conceptualisation of access to healthcare. I have emphasised the importance of moving beyond understandings of access to healthcare which stress measures of health service

uptake and physical distance to caring services, towards a detailed understanding of access to healthcare which is sensitive to the experiences and perspectives of South Asian women.

My study adds to work on access to healthcare by emphasising that it is inappropriate to examine the issue of access to healthcare without referring to people's views and experiences. Where health policy is increasingly meant to be consumer sensitive and where health promotion is about enabling people and is based on the principle of community participation and development (Douglas, 1995), my broader conceptualisation of access together with my findings have challenged the idea that women's own healthcare knowledge is less important than that of health professionals. It follows that women's views are resources for policy formulation and need to be fed into the training of health professionals and administrators. Given the increasing use of indicators of successful performance in health services, my findings emphasise that people's experiences and perspectives need to be integral to this process.

My findings also stress the importance of understanding and learning from the perspectives of marginalised groups in order to inform policy and practice. In terms of work on minority ethnic groups, the need to understand South Asian women's healthcare experiences and perspectives is all the more important if we consider that in the past, issues in the study of minority ethnic groups' health and healthcare have tended to be shaped by outsiders using anecdotal evidence, rather than investigated empirically, and that these 'conventional' understandings of minority ethnic groups' access to healthcare have informed health policy, planning and practice (see chapter 1). The views of minority ethnic groups are also important as they challenge the 'intellectual apartheid' (Ahmad *et al.*, 1989c: 54) in studies on minority ethnic groups and health, where minority ethnic groups are excluded from studies about themselves.

Findings drawn from the healthcare experiences and perspectives of 36 South Asian women lead me to my **second conclusion**, which is that women's accounts of access to healthcare are linked to their life experiences. My findings have shown that healthcare is more than just a series of medical interventions. It is not an isolated event, but part of everyday life, forming part of a web of life experiences. Healthcare then has wider significance than its separation out for pragmatic reasons in social policy might suggest. The interview data have shown that healthcare needs to be seen in the context of women's daily lives and interactions. For example, in all healthcare arenas the data have shown that women's

accounts of their healthcare are meshed with accounts of their daily lives and with the experiences of others such as family and friends. Both clearly inform women's perceptions of health, health behaviours, perceptions of health services and patterns of health service use. This means that if we want to enhance the healthcare of South Asian women and deliver effective services we need to look at ways in which healthcare is incorporated into and impacts on everyday life, and at ways in which life experiences impact on access to healthcare.

A broader conceptualisation of access to healthcare and women's accounts of healthcare in their daily lives have shown that access is mediated by a number of factors and has a number of different dimensions - individual, collective and physical. This has provided my analytical framework for understanding South Asian women's access to healthcare. The findings at the individual level have focused on individuals' health actions, experiences and key concerns. At the collective level the findings have focused on factors that are beyond the control of the individual and affect everyone in similar circumstances. These set the findings in the collective social environment. At the physical level the findings have examined dimensions of access concerned with physical distance which, as argued in chapter 1, are often stressed in the literature on access to healthcare.

The findings in all dimensions of access lead me to my **third conclusion**, which is that access issues differ from conventional understandings about South Asian women's access to healthcare which have informed previous studies, policy positions and research foci. My findings have shown that South Asian women's experiences of healthcare are more diverse than much of the literature acknowledges. It is important for studies on minority ethnic groups to draw on the diversity of views and experiences that exist among minority ethnic groups. In the current study, such a practice has provided evidence which has allowed me to challenge and modify conventional understandings at a number of levels. It is important to recognise that four South Asian ethnic groups were represented among the women interviewed and that the women differed in terms of age and lifestage. It is also important to emphasise that when analysing the data, every effort was made to uncover any differences in women's perspectives and experiences, for example according to ethnic category. In the end, however, the data on access to healthcare have suggested that there was more variation in experiences and perspectives within the South Asian ethnic categories

than between the categories and that the women interviewed were exposed to many common experiences.

At the *individual level* my findings have challenged the pathologisation of South Asian women's health behaviours both outside health services and when using the GP service and cervical cytology services. My findings have also challenged a variety of stereotypes of South Asian women's health behaviours. In particular, I have shown that South Asian women are keen to improve their health and healthcare, both through service use and through health practices which do not involve formal health service use. The accounts have shown that the women interviewed hold strong ideas about their health and healthcare and exhibit a variety of patterns of healthcare, health needs, and healthcare experiences in their daily lives. The accounts have challenged the idea, suggested in some studies, that South Asian women use the GP too much, mainly for trivial complaints (Ahmad *et al.*, 1991b; Fenton, 1987; Wright, 1983). They have also contested the assumption that South Asian women are not interested in and do not use preventative healthcare services such as cervical cytology, which is also referred to in other studies (Bowes and Domokos, 1995a, 1993; NAHAT, 1995; Bradley and Friedman, 1993; Anon, 1991; Barker *et al.*, 1984). South Asian women are enthusiastic about and keen to use health services, are overwhelmingly users of mainstream health services and want to receive health promotion messages and preventative treatment in accordance with NHS policy.

My study reinforces the need for work on minority ethnic groups and health to provide empirical evidence to challenge stereotypes and conventional understandings of minority ethnic groups' health behaviours. This is important as argued in chapter 1, stereotypes and anecdotal evidence have informed understandings of and questions about minority ethnic groups' access to healthcare, understandings of minority ethnic groups' health behaviours and health needs as well as health policy. Empirically based studies, like the current study, are also important because, as noted in chapter 1, the effects of stereotyping on access to healthcare remain under-investigated (Ahmad, 1994), especially from the point of view of minority ethnic groups themselves. This set of findings also adds to work on women's health. Where the academic and popular press have been preoccupied with the abnormal and women's health *problems* as if 'women cannot be well any more' (Annandale and Clark, 1996: 29), my work has emphasised that understandings of access to healthcare need to be informed by empirical data focusing on the ways in which women support and

maintain their own health and the ways in which women act to enhance their access to healthcare.

Also in contrast to conventional understandings about South Asian women's access to healthcare, it is clear that the similarities in South Asian women's healthcare ideas and practices outweigh the differences between them and other women cited in the literature. This finding is important as it challenges the literature on minority ethnic groups and health that has emphasised the distinctive healthcare practices of minority ethnic groups and has marginalised ideas about gender difference in research on minority ethnic groups and healthcare.

At the *collective level* access issues also differ from conventional understandings about South Asian women's access to healthcare. Importantly, my findings add to work on minority ethnic groups and health by challenging the use of stereotypical and simplistic notions of South Asian culture in explanations of South Asian women's access to healthcare. Chapter 1 showed that work in the field has tended to see culture as a rigid concept which mechanistically determines minority ethnic groups' health behaviours and actions. It also showed that ideas about access to healthcare have been linked to the supposedly pathological cultures of minority ethnic groups. For example, constructions of South Asian culture have encouraged the view that culture is problematic and the view that South Asian culture acts to deny South Asian women's access to health services and so-perceived healthcare opportunities. I have argued that the constraints on access imposed by constructions of South Asian culture are frequently identified in previous research and in training material for health professionals. They have also been picked up by health professionals and informed health policy. These ideas about culture have a number of broad implications for understanding minority ethnic groups' access to healthcare. Two of the main implications are as follows: Firstly, understandings of access to healthcare that draw on stereotypical constructions of South Asian culture have meant that the solutions to access problems become located in the culture of minority ethnic groups rather than in the realm of the healthcare provider. Secondly, such explanations do not consider 'structural' explanations for inequalities in access to healthcare or the healthcare experiences of minority ethnic groups. This has meant that the 'race' and gender dimensions of access have become submerged (see also my discussion below).

Chapter 1 reported that constructions of South Asian culture are exoticised, frozen and have commonly been defined by outside observers. They have emphasised a set of customs, for example consulting a *hakim*, a distinctive diet, family structure or the distinctive treatment of women. These constructions have meant that culture is reduced to a set of things rather than a dynamic force that sustains and nurtures people (Ahmad, 1993a).

My findings add to work on minority ethnic groups and health by confirming that in the stereotypical 'set of things' sense, culture is unimportant to a study of South Asian women and their access to healthcare. My study has argued that if more useful ideas about culture are adopted and culture is defined as people's world view, which draws on a shared fund of ideas or culture and an individual's lived experience (Bowes, Dar and Sim, 1995), then culture is a set of resources that South Asian women draw upon to negotiate their lives and cultural factors are important in South Asian women's access to healthcare. For example, chapter 3 reported that women feel their health and healthcare practices can be enhanced. These feelings are better resources and greater influences on access to healthcare than static, homogeneous and racist notions of South Asian culture. It follows that the perspectives of South Asian women themselves and the wider context of their lives need to be taken into account to challenge conventional understandings of South Asian women's access to healthcare.

My study has challenged explanations of access to healthcare which focus on constructions of South Asian culture in a number of ways. Firstly, the data provide little evidence for a set of distinctive, inclusive, exotic and homogeneous cultural factors mediating access to healthcare. I have argued throughout this thesis that the healthcare patterns of the South Asian women interviewed show variation rather than consistency due to culture. I have also shown that many of the factors influencing South Asian women's healthcare behaviours and practices are, in fact, shared with other sections of the population. Secondly, in another challenge to conventional static conceptions of culture, the interview data do not support the idea of a distinctively Pakistani or Bangladeshi way of negotiating access to healthcare. As noted above, there was more variation in women's experience within ethnic categories than between ethnic categories and there were commonalties in experience across ethnic groups. Thirdly, many constraints on access as conventionally thought of are unrelated both to the healthcare experiences as well as the life experiences of South Asian women. Fourthly, South Asian women are more active in their healthcare than conventional understandings of access, which draw on constraints posed by conventional understandings of South Asian

culture, might have us believe. Finally, the data have revealed a number of other factors affecting access to healthcare among the South Asian women interviewed. The data have shown that the women emphasise the external structural and exclusionary processes and the socio-economic context of health. They do not see their culture as affecting access to healthcare. But their accounts do suggest how cultural stereotypes can act as a form of racism, and therefore as an exclusionary force. They cite instances where their access to healthcare has been compromised by wider collective forces in society. The women's accounts turn our attention toward the effects of racism and sexism on access to healthcare (see below).

At the *physical level* my analysis has shown that South Asian women do not experience physical constraints on access as conventionally thought. Medical geography and the geography of healthcare have been preoccupied with conventional notions of spatiality that focus on distance to, and the distribution of, health services. Hence conventional understandings of access have been organised around physical space. Notwithstanding that this work on health service availability is important, my study complements conventional ideas about the physical dimensions of access. My findings add to work on access to healthcare by suggesting that studies need a broader understanding of spatiality since conventional understandings of physical constraints on access are not sensitive to a range of differences and inequalities that exist among social groups. Therefore they need to be modified if the concerns of South Asian women are to be represented. This finding adds to current work on minority ethnic groups which recognises that many concepts employed in social science and health services research are not sensitive to the experience of minority ethnic groups and need to be modified (Ahmad, personal communication and work in progress on socio-economic position and health).

To express the concerns of South Asian women, my study has shown that understandings of access around physical space are enhanced by, and are meshed with, other collective dimensions. The findings add to work on access to healthcare as they have suggested that other dimensions of access may be more or equally important than the physical dimensions of access to healthcare. Where the women did express concerns about the use of health services or other sources of healthcare due to their location or constraints on mobility, in many cases their concerns were bound up with other issues. These included the obligations attached to gender roles, concerns about and experience of racism in the wider environment and about the use of spaces outside the home, such as health services.

I have shown that the physical dimensions of access do affect the healthcare choices of the women interviewed. The main problems were getting to places such as formal health services as well as problems of access to public and private transport in order to use health services and to gain other sources of healthcare including support from friends and family. The data have also revealed problems with using specialist services, such as cervical cytology or Family Planning Clinics, that might be further away than community healthcare provision.

In another challenge to conventional ideas around physical access, my study has shown that the concept of access not only depends on the positioning of services but also on the positioning of different groups of people. South Asian women, on account of their social position, have to deal with other distancing and exclusionary mechanisms in their experience and patterns of healthcare. These are often meshed with ideas about 'race' and gender difference. I have also shown that where people are, affects access to healthcare. The spatial proximity of sources of social support such as family and friends, including other South Asian women, has been shown to be an important factor affecting the women's access to healthcare in all three chosen healthcare arenas.

These ideas about social positioning lead me to my **fourth conclusion** which is that South Asian women's access to healthcare is inseparable from their experience of 'race' and gender difference. The findings have suggested that ideas about 'race' and gender difference mediate access to healthcare for South Asian women and that this occurs despite the diversity of healthcare needs and practices among those interviewed. Ideas about 'race' and gender difference affect all levels of access and are seen throughout the findings from the three healthcare arenas. The findings have suggested that the effects of ideas about 'race' and gender difference mediate the health choices, healthcare opportunities, health actions, pathways into and through health services, patterns of service use and the healthcare experiences, of South Asian women. Work in the field of minority ethnic groups and health should not, therefore, neglect the structural contexts of minority ethnic groups' lives.

This study has underlined the importance of the gender dimensions of South Asian women's access to healthcare. These findings add to work on minority ethnic groups and health by providing evidence to support other work which challenges the marginalisation of gender issues in research on minority ethnic groups. Such findings are important as debates in the field of minority ethnic groups and health have generally centred around conventional

understandings of South Asian culture or to a lesser extent 'race' difference, leaving the gender dimensions of minority ethnic groups' experience unseen. In some ways this reflects the legacy of culturally deterministic research which, as noted in chapter 1, tended to concentrate on the differences rather than the commonalties between minority and majority ethnic groups, and tended to redefine health issues for minority ethnic groups and to use a different range of explanations for minority ethnic groups compared to the majority ethnic group.

As noted above, the data have illuminated similarities in the variety of health practices between the South Asian women interviewed and other categories of women documented in the literature. My findings have shown that the women interviewed hold strong ideas about health and healthcare, are key maintainers of family health and are unpaid health workers. In addition, they have shown that South Asian women experience constraints on access to healthcare experienced by other women, as shown in the literature on women's health. The obligations attached to gender roles and ideologies of women's position in relation to caring responsibilities act to constrain the women's own healthcare choices and actions. They affect the way that healthcare is used, their pathways into services, their decisions to use services, patterns of service use including attendance for screening and screening regularity, as well as their experience of healthcare. The gender dimensions of access have also been shown to affect women's ideas about the importance of health, worries about health and their actions to maintain health and cope with ill health.

Where distinctions may be drawn between South Asian women's access to healthcare and other women's access revealed in the literature, these relate to the processes of exclusion, which we call racism. The data have shown that racism is an important factor shaping South Asian women's healthcare experiences. It ensures that South Asian women's experience of healthcare is qualitatively different from that of other women documented in the literature. Firstly, racism has been shown to increase the importance of health and healthy behaviours for the South Asian women interviewed. Secondly, it has been shown to affect well-being especially psychological health. Thirdly, racism has been shown to be a hazard to health by acting to constrain South Asian women's use of health services. For example, I have shown how women's experience of racism may affect the uptake of services. It may make women think twice about using health services, affect the problems that they feel they can take to services and the role of the GP in their healthcare. Stereotypes of South Asian women's health behaviours may add to the processes of muting in South Asian women's experience

of cervical cytology services and may contribute to women's lack of knowledge about the service and the procedure. Fourthly, it has been argued that racism reinforces the pathologisation of South Asian women's healthcare behaviours. The interview data have shown that racism operates in a number of ways, both consciously and subconsciously and takes a variety of forms - interpersonal and institutional.

These findings add to work on women's health in a number of ways. They are important because debates on women's health and healthcare have tended to focus on ideas about gender difference and have underplayed the effects of racism. My study has shown that the factors affecting South Asian women's access to healthcare are not all related to ideas about gender difference and that ideas about gender difference are not the only determinant of women's fate or the ultimate cause of oppression for all women (Annandale and Clark, 1996). As noted above, other factors, including ideas about 'race' difference, come into play in South Asian women's experience of access to healthcare.

Further, my study adds to work on women's health as it challenges the tendency in work on women's health to universalise women's health experiences (Annandale and Clark, 1992). For example, it has emphasised the diversity of experience among the women interviewed. It has also challenged the idea that all women are able to act on their health in the same way and negotiate their access to healthcare in the same way. And, it has argued that women's health behaviours cannot be assumed. This is important. The tendency to universalise women's experiences has inhibited our ability to understand women's experiences (Annandale and Clark, 1996), it has privileged the experience of white women (Phoenix, 1992) and has helped to reinforce the invisibility of minority ethnic women in research on women's health.

In addition, my study has argued that work on women's health needs to be sensitive to differences amongst women. This adds to other work on women's health which has stressed the need to challenge the 'silence around differences between women' and the silencing of different needs among women (Annandale and Clark, 1996: 30). This is also important as the universalistic assumptions behind much research on women's health have helped to draw attention away from differences (for example in healthcare experiences and perceptions) within women as a group. They have also drawn attention away from commonalities that cross cut ethnic groups.

My findings have stressed the importance of locating South Asian women's health behaviours in the context of ideas about gender difference *and* in the context of ideas about 'race' difference. Further, they have suggested that, when referring to experience of South Asian women, it is inappropriate to talk about ideas about 'race' difference or ideas about gender difference in an abstract way. As noted in chapter 1, research has tended to see minority ethnic women either as members of a racialised group or as women (Bhavnani, 1993). Work on women's health, therefore, needs to include different ways of conceptualising gender-based experience, if it is to represent the complexities of women's lives and the experiences of other groups of women. This adds to my discussion in chapter 1 which argued that the literature on women's health has been generally 'race' blind and that it has neither understood nor challenged the position of minority ethnic women.

The evidence presented in this thesis has suggested that access to healthcare is affected but not determined by 'race' and gender difference, or by culture in the sense described above. My findings challenge the over-emphasis on any one factor in structuring access to healthcare for South Asian women. As noted in chapter 1, debates about minority ethnic groups and healthcare have centred around culture and to a lesser extent 'race' and gender difference, and debates on women's healthcare have commonly assumed that the experience of all women is predominantly circumscribed by gender. My findings have suggested that racism compounds the processes structuring gender disadvantage in healthcare. Both factors contribute to the disempowerment of women in their healthcare.

The structural position of all four South Asian ethnic categories ensured that the women interviewed shared the experience of racism. The data have emphasised that the women perceive differential treatment for South Asians compared to other ethnic categories and either talk about their own treatment and fears and/or extend them to other people of South Asian origin. The interview data have also shown that South Asian women vary in the forms and degrees of racism they face. This includes their experience of, views of and responses to, the effects of racism on access to healthcare. Further, the findings have shown how the women interviewed negotiate access to healthcare in the face of constraints and are active in their healthcare (see also discussion below).

These findings have implications for future work on minority ethnic groups and health. In particular, they point to the need to challenge determinism in explanations of minority ethnic groups' health behaviours and access to healthcare. They also highlight the need to

consider a range of factors when examining minority ethnic groups' healthcare experiences and access to healthcare.

Gender and 'race' dimensions of access operate not only outside, but also inside health services. Both dimensions have been shown to affect South Asian women's perceptions and experiences in all three healthcare arenas. This adds to work on access as it challenges understandings of access to healthcare which have focused solely on health services. It has been suggested, therefore, that health services mirror and reproduce ideas about 'race' and gender difference.

These findings lead me to my **fifth conclusion** which is that access to healthcare for South Asian women is affected by the attributes of health services. This means that when identifying the factors that affect access it is essential to examine the attributes of health services. This adds to work on minority ethnic groups and health. Chapter 1 showed that understandings of access have concentrated on the attributes of minority ethnic groups rather than on minority ethnic groups' experiences and perspectives of healthcare and the attributes of services. My findings have shown that access issues for South Asian women, relate to the service provider rather than to the consumer. This set of findings also adds to work on access by showing that healthcare needs to be placed in the context in which it is made available. Access to healthcare is bound up with how services are provided and is linked to the appropriateness of provision, service availability, the way that care is offered to women, service environments and the quality of care. Therefore, it seems reasonable to suggest that health services must consider their own practices in relation to South Asian healthcare users and that health services have a clear role to play in ensuring the accessibility of services for South Asian women both in policy and provision, and through the practices of health professionals themselves.

This leads to my **sixth conclusion**, namely that health professionals can play a role in constraining access to healthcare for South Asian women by reproducing and reflecting ideas about 'race' and gender difference. This study has highlighted ways in which social difference seems to be amplified by the attitudes of healthcare providers and the culture of service provision. I have illustrated ways in which health professionals may help to define minority ethnic groups as different, as well as ways in which social boundaries between social groups are maintained. Difference is made significant through the processes of muting and institutional racism, for example, where health services do not provide for,

support or recognise the communication needs of South Asian women. Such boundaries may be also maintained through the use of cultural stereotypes in women's health service experiences. This finding is important, like the findings above, it challenges understandings of minority ethnic groups' access to healthcare which have concentrated on the attributes of minority ethnic groups rather than on minority ethnic groups' experiences and perceptions and the attributes of health services.

One of the biggest problems of the service provider is that they may operate from a culturally stereotypical (ethnocentric) point of view. This may make service delivery and access to healthcare problematic. The interview data have shown that assumptions about South Asian women and their health behaviours contribute to the negative access experiences of this group. For example, South Asian women may suffer from the expectation that they will be 'problem patients', that they will use services in particular ways, have particular health problems or cope with them in certain ways on account of ideas about 'race' difference or ethnicity. In addition, my findings have shown that the use of cultural stereotypes obscures the health needs of individual women. The employment of stereotypes creates barriers which the women need to negotiate before obtaining health services. My findings have strongly suggested that where misrepresentations of South Asian women continue to be used by health professionals, and where health service practice does not move to challenge them, health services are implicated in the reproduction of stereotypes of South Asian women.

As a result the data suggest that the patterns of healthcare of some South Asian women are shaped in response to racism and sexism. This is my **seventh and final substantive conclusion**. A focus on three different healthcare arenas has allowed me to show that this occurs both inside and outside health services. The data have suggested that racism and sexism inform women's perceptions about the role of health services in their own healthcare and affect their healthcare experiences.

The findings have suggested that women have to balance constraints on access to health services against not using health services at all. Once again this adds to work on minority ethnic groups and health by challenging determinism in explanations of minority ethnic groups' health behaviours as highlighted in chapter 1. As noted above, the women are enthusiastic about, and keen to use, health services. Their accounts have shown that they expect equal access to health services but that their expectations are not always borne out by

their healthcare experiences. The accounts reflect the ideal of equality of access that is enshrined in the NHS, and reveal ways in which South Asian women might fail to gain their rightful access to healthcare and in which the welfare ideal is compromised for this social group. The data have shown that the women interviewed are clearly concerned about the access experiences of South Asian women more generally. This was demonstrated where the women extended their own experience to, and drew on, the healthcare experiences of other South Asian women.

The accounts have shown that women negotiate racism, sexism, their effects on access to healthcare and the culture of health service provision in a number of ways. Many women use strategies to enhance their access to healthcare. These 'strategies for access' help to prioritise the women's own interests, and to 'soften' the constraints that they encounter both in health services and in day to day healthcare.

One of the most important strategies that has been outlined is the use of social support to enhance women's healthcare opportunities. The findings have shown that the care provided by others, especially other women, is particularly important in the active management of women's healthcare. The role of social support in the healthcare of the South Asian women interviewed must be seen against the constraints on access to healthcare experienced by them. I have noted that women's use of social support does not align with ideas about the stereotypical support network in South Asian communities which supposedly provides an alternative to welfare transfers. Social support has been shown to provide a route into welfare and may act as a substitute. It may allow women not only to gain healthcare ideas, but also to harness health services and forms of healthcare and to compare and learn from their healthcare experiences. Social support may help to provide childcare and practical assistance to allow women to attend health services and to enhance their healthcare opportunities, thereby allowing time to maintain health by 'easing' some of the obligations attached to gender roles. Included in the data on social support is the women's voluntary sector which plays a central role in enabling access to healthcare. Where the literature on access to healthcare points primarily to the disadvantage of minority ethnic groups with regard to access to health services, as shown in chapter 1, these findings suggest that informal support networks, reciprocal support and care provided by family and friends may mean that inequalities in access to healthcare for South Asian women are not as great as they might otherwise be.

Other 'strategies for access' that have been identified in the data are more covert. Some women challenge assumptions about the health attitudes and actions of South Asian women by avoiding racist or stereotypical representations in their interaction with health services. The data have shown how women may avoid services, may not ask for help, or gloss over access difficulties. 'Strategies for access' also include the use of other sources of support including complementary medicine and the use of facilities in the voluntary sector. Such 'strategies for access', I have argued, may be shaped in relation to wider constraints on South Asian women's access to healthcare as outlined above.

In this study I have explored access to healthcare for South Asian women in three different healthcare arenas. The aim was to move away from conceptualisations of access as uptake and distance to caring services, toward a detailed understanding of access that was sensitive to the views and experiences of South Asian women. It was important to progress from studies on minority ethnic groups and healthcare that have centred on quantifiable measures of health status and disease, and to focus on the perceptions and experiences of South Asian women. The findings add to work on access by confirming the importance of user views to understandings of access to healthcare. I have argued that we cannot take for granted the factors which affect access to healthcare for this group of women and shown that a number of individual and collective factors, including 'race' and gender difference and culture as women's world views, affect access to healthcare for South Asian women.

In addition to my substantive conclusions on matters of access to healthcare, this study produced some insights into qualitative methodology and research with minority ethnic groups. The next section summarises my methodological conclusions.

6.3 Methodological conclusions

Chapter 2 emphasised that research practice is important if we are to broaden our understanding of access to healthcare for South Asian women. The aim throughout has been to focus on South Asian women's perspectives and experiences of healthcare and my study has stressed the importance of enabling women to speak so that their views and concerns can be identified in order to inform understandings of access to healthcare, healthcare provision and policy.

Where past healthcare research has tended to be over-cautious in approaching South Asian women (Douglas, 1995), I conclude that it is possible to consult South Asian women in one to one meetings using open-ended and reflexive questioning that is responsive to their own views. Research practices which aim to promote informality, reflexivity, and sensitivity, provided an environment which encouraged women to talk about their experiences and perspectives of healthcare. The result has been an increased understanding of the range and diversity of access issues from the accounts of South Asian women themselves.

A number of lessons were learned when working with qualitative methods on this topic. In chapter 2, I have emphasised the exploratory nature of qualitative research techniques. In terms of the wider literature on minority ethnic groups and health, qualitative methods were particularly useful as they enabled me to move away from past quantitative studies that have used ethnicity as an independent variable and focused on measures of health and disease, at the expense of the perceptions and experiences of minority ethnic groups themselves.

Qualitative methods played an important role in allowing me to uncover a range of contextual factors that affect South Asian women's access to healthcare. In terms of health research more generally, semi-structured interviewing techniques were useful as they helped me to gain an understanding of specific episodes alongside women's general views and experiences. I conclude that such contextual data is of particular importance in research on minority ethnic groups and health. As noted in chapter 1, research in the field has tended to focus on a particular disease or health problem. The use of more contextualised information from the accounts of minority ethnic groups encourages research to focus on issues other than the disease and to focus on the realities of minority ethnic groups' lives and the non-health problem specific factors that might affect minority ethnic groups' access to healthcare. In my study, the use of semi-structured interviewing techniques also allowed women to define access patterns in ways meaningful for them. This is important as I have argued in section 6.2 that it is inappropriate to examine the issue of access to healthcare without reference to people's views and experiences.

Further, qualitative methods played an important role in capturing the diversity of minority ethnic groups' experiences and perspectives. In my study they helped me to examine a wide range of factors affecting South Asian women's access to healthcare. Methods that aim to uncover a range of views and experiences are especially important in this field. For example, the range women's views and experiences in this study have been used to

challenge a number of conventional understandings about minority ethnic groups and healthcare. In particular, they have been useful in helping me to challenge the over-emphasis on certain factors, for example, constructions of South Asian culture and ideas about 'race' difference, in explanations of minority ethnic groups' health experiences and health actions.

Qualitative methods also allowed me to increase the depth of the data gained. This has enabled me to draw conclusions that could not have been drawn from responses to standardised and closed ended-questions used in more quantitative work. For example, the interactive nature of semi-structured interviewing techniques assisted the emergence of issues that were not covered in the initial interview questions. Social support, in particular, emerged as an important issue affecting South Asian women's access to healthcare. In addition, the complex data gained through the use of qualitative methods have also allowed me to highlight similarities in women's experiences. This is important. As noted in section 6.2, the literature on minority ethnic groups and health has tended to emphasise the differences between ethnic groups. A number of other dimensions of the research process also helped to enhance the understandings gained. These are discussed below.

Contact with the women's voluntary sector contributed to the understandings gained and the smooth running of the research project. Such an approach alerted me to issues not addressed in the literature. For example, it gave me prior knowledge of the research situation, local knowledge, alerted me to potential obstacles to be overcome, assisted ways of approaching other groups and individuals, and suggested ways of approaching sensitive topics. Without the support of these groups and individuals this study would have been more difficult or even impossible and it would certainly have prolonged the data collection phase of the project.

Further, snowballing as a means of finding potential interviewees contributed to the timely completion of the interviews given the small and, in some respects, dispersed South Asian community in Edinburgh. This process helped me to gain access to a variety of women, from four South Asian ethnic categories, with a range of healthcare and life experiences. This method of sampling was especially important in the face of the limited time and resources available for gaining access to the women I needed to interview.

In addition, advocates and key informants also assisted the project at all stages, from research design and interpreting, to providing background information about the women

interviewed and assisting the clarification of interview data. My experience has shown that this methodological approach was essential in establishing some form of shared understanding about the aims of the project. The latter proved to be important in contacting potential interviewees and in ensuring the smooth running and timely completion of the project.

I conclude that contact with the voluntary sector, the use of snowballing and the help of advocates and key informants are important methodological approaches that might assist other studies focusing on marginalised groups and/or small populations. My experience has shown, however, that such approaches require a large amount of groundwork and that ample time and resources (e.g. for travel, telephone calls and remuneration) need to be scheduled in to project outlines.

Finally, I have shown that understandings of access to healthcare for South Asian women were enhanced by the methods used to analyse the findings. Computer assisted qualitative data analysis (CAQDA) enabled the data to be managed quickly and efficiently, allowed the analysis to be more rigorous and less impressionistic and helped me to draw attention to the full range of findings. CAQDA assisted in maximising my findings by allowing me to consider their depth and breadth, including majority and minority views. In terms of research on marginalised groups, I conclude that this approach to the analysis of qualitative data is all the more important when examining the voices of those who are less easily heard in research, services and policy especially where, as I have shown in chapter 1, others have spoken for South Asian women and assumed their healthcare behaviours and needs. In terms of the use of qualitative data to inform policy and service planning, where unsystematic qualitative data analysis has been criticised in the past (Opie, 1992), the use of CAQDA to encourage systematic data analysis is also important in order to challenge the tendency to disregard qualitative data in policy design (Phillips and Rathwell, 1986: 17) and the selective use of such data to support decisions about resource allocation (Stubbs, 1993).

These dimensions of the research process have been shown to be crucial in facilitating women's voices to allow me to understand the enablements and constraints on South Asian women's access to healthcare in three healthcare arenas. They were also important in enabling me to learn from the perspectives and experiences of the women interviewed. The methodological approaches taken and my substantive conclusions raise a number of further questions that might be tackled in other studies. This is the subject of the next section.

6.4 Issues for further research

My research identifies a number of issues for further research in areas related to women's access to healthcare. These fall under three main headings. Firstly, more work is needed focusing on minority ethnic groups and further aspects of healthcare. Secondly, there is room for further study in areas specific to my three chosen healthcare arenas. Finally, there is scope for further work in areas which arose from an evaluation of the methodological approaches taken.

Further aspects of healthcare

There is scope for further work focusing on minority ethnic groups and aspects of healthcare other than those addressed in this thesis. These studies could also be designed to explore the experiences and perspectives of minority ethnic groups themselves and the effects of culture and ideas about 'race' and gender difference on access to healthcare. This study focused on primary healthcare provision but my findings could be extended by an examination of other aspects of preventative healthcare provision such as immunisation, other types of screening such as breast screening and health checks as well as an examination of aspects of secondary care. Some of the women drew on their experiences of maternity care when describing their experiences of the GP service and of cervical cytology. They described how the learned patterns of service use may affect the role of the GP in their healthcare, communication in consultations and their attitudes to cervical cytology. On the basis of these experiences, it seems plausible to suggest that more research might usefully be designed to examine South Asian women's experience of maternity care. This could assist an understanding of the negotiation of, and the issue of access to, healthcare by South Asian women. My study has drawn some links between formal healthcare provision and healthcare outside health services and this link too might provide the focus for a more in-depth study able to shed light on the negotiation of healthcare among minority ethnic groups.

I have raised the issue of links between racism and sexism inside and outside formal health service provision as well as the need to understand the processes of exclusion which affect South Asian women's access to healthcare. More in-depth work might be designed to examine women's perceptions and experiences of racism and sexism, the dynamics of these factors and their effects on access to healthcare. This should include an assessment of the effects of racism and sexism on health and well-being, especially on mental health. My

study has also suggested that South Asian women's patterns of healthcare may be shaped in response to racism and sexism. Further in-depth work might be designed to examine the effects of both factors on minority ethnic groups' healthcare practices, beliefs and use of health services. As noted in chapter 1, it is important to identify where and how factors such as racism and gender bias operate if they are to be challenged, otherwise the case against each factor is diminished.

Another area that needs more attention is social support in the healthcare experience of South Asian women. This issue was not the main focus of my study and this has meant that my findings are exploratory and only examine social support and access to healthcare in general terms. This means that there is scope for more specific work in this area. My study has given some idea of the extent of, and limitations on, social support in South Asian women's healthcare and has challenged the idea of a South Asian family support network. It was, however, only possible to make general comments about social support and health and ill health. I suggest, therefore, that further work might usefully examine the importance of social support in minority ethnic groups' healthcare according to health status. My findings have indicated differences in access to forms of social support according to age and lifstage. Further work might also consider the importance of social support in the healthcare of minority ethnic groups in relation to these factors.

Another focus of interest to arise from my findings is the existence of different types of social support in South Asian women's access to healthcare. Studies might be designed to consider administered and perceived social support and the nature and extent of each type. I have shown that some women feel that they do not have enough of this type of support. A further study might examine South Asian women's needs for social support in their healthcare. This should include the role of the women's voluntary sector in their healthcare. As noted above, one issue to arise from the data on social support is that there are limits to the role and extent of social support in South Asian women's healthcare and that social support can either enhance or constrain access to healthcare for the women interviewed. I suggest, therefore, that the negotiation and nature of social support also requires more investigation. This might include an examination of whether social support is requested by women or is spontaneous as well as an examination of the interaction between types of social support within and outwith the family. A further valuable area of work might examine the interaction between social support and minority ethnic women's access to health services. Chapter 3 suggested that social support might be used in response to health

services and that the effects of social support may mean that inequalities in access to healthcare for South Asian women are not as great as they might otherwise be.

The findings on social support have also raised the issue of the role of health visitors in the healthcare of the South Asian women interviewed. This might also form a focus of inquiry. The interview data have indicated that the effectiveness of the role of health visitors and GPs in the women's healthcare is linked to communication. A further study might consider differences in communication between South Asian women and these two types of health professional (work in progress Bowes and Domokos, Stirling University). The data have also highlighted the need for a clearer picture of the views of health professionals towards minority ethnic groups. Although this was not the focus of my study, the views of health professionals would provide further insight into the issue of access to healthcare for minority ethnic groups.

Further study in the three chosen healthcare arenas

There is also scope for further study centring on a number of themes arising from my findings in the three healthcare arenas. Chapters 3 and 4 have presented exploratory findings on women's subjective assessments of mental health concerns and on their use of the GP for these concerns. More specific work might examine South Asian women's strategies for dealing with stress and worries in their everyday lives. A further examination of access to services might consider women's perceptions of the use of health services for non-physical health concerns and their knowledge of services available. This should include specific questions about the extent to which health services and the learned patterns of service use contribute to women's 'mistrust' of the use of health services for such concerns. There is scope to examine the extent to which women feel these types of health needs are met by health services, including services outside GP care, and to examine the demand for counselling services among minority ethnic women.

Chapters 4 and 5 highlighted the twin themes of communication and information flows in women's experience of the GP service and cervical cytology. More specific research might be designed to consider information flows between health professionals and health service users within the consultation. This might include questions on what women, as users, want to know and why, and the effects of information flows on their access to healthcare. It might also include an assessment of health professional's views and experiences of giving health information to minority ethnic groups. This would add to an understanding of the

effects of communication (in its widest sense beyond language problems) on minority ethnic groups' access to healthcare. Chapter 4 has shown how communication factors may affect women's patterns of GP use and their compliance with care, for example with prescribed medicines and dietary advice. The effects of communication between service providers and service users on patterns of service use and compliance with care also require further investigation.

There is also room for further studies focusing on informal information flows outside consultations with health professionals and examining their effects on access to health services. This is seen especially in chapter 5 which examined information flows about cervical cytology and explored how and why women gained screening information in particular ways. Given that social support has been shown to be an important and unrecognised resource in enabling access to cervical cytology and that many women felt that they wanted to know more about cervical cytology, further work could examine the potential use of informal information flows in order to fill gaps and eradicate misunderstandings in women's knowledge about cervical cytology and to spread information on sensitive topics in relation to screening. The latter might include knowledge about risk minimising behaviours and questions about the appropriateness of information about cervical cancer, cancer more generally and HPV. Also in chapter 5 the women referred to other people's levels of knowledge about cervical cytology and its implications for women's access to the service. Women's perceptions about other women's attitudes toward cervical cytology and men's lack of knowledge about women's health issues mean that further useful work might be designed to examine both men and women's attitudes toward screening more generally.

The data have highlighted the diversity of healthcare practices, experiences and needs among the women interviewed and this too raises a number of possible areas for further examination. Firstly, my study has pointed toward the effects of lifestage and generation, for example, on women's perceptions of health and healthcare needs and their attitudes toward information flows about cervical cytology. The effects of lifestage and generation on access to, and patterns of, healthcare require more investigation. One area for further study might be older minority ethnic women's attitudes to, knowledge and experience of cervical cytology. This information is needed to inform healthcare providers. It is particularly important given that the objective risk of cervical cancer increases with age. Secondly, some of the women made comparisons between the experiences of South Asian women and South Asian men when talking about their health. Another useful comparison

might be drawn between the health experiences of, and the use of health services by, these two groups. The literature on the health of minority ethnic men remains limited.

Finally, my work is unable to draw any firm conclusions about the effects of socio-economic status on South Asian women's access to healthcare. The Black Report (Townsend and Davidson, 1982) highlights inequalities in health according to socio-economic status among the general population, however, it makes little reference to minority ethnic groups. It seems reasonable to suggest nevertheless that socio-economic status may make a difference to the health and healthcare experiences of minority ethnic groups, which are, after all, differentiated by socio-economic status. Some useful work might compare the healthcare experiences among South Asian women in different socio-economic groups.

Issues for further research arising from the methodological approaches taken

The methodological approaches taken and issues arising from the implementation of the methodology also raise a number of issues for further work. There is scope for further study on the sensitivity or otherwise of discussing certain topics. This study and others (Bowes and Domokos, 1996) have shown that sensitive topics for South Asian women differ from conventional understandings. A larger study with more resources would be able to evaluate a range of strategies for interviewing women about sensitive topics and compare the responses gained. Knowledge of sensitive topics would help to increase an understanding of the issues affecting access to healthcare for South Asian women. This needs to inform healthcare professionals and is important as conventional understandings of sensitive topics have informed understandings of South Asian women's health, informed other studies focusing on South Asian women, affected the inclusion of minority ethnic groups in research and affected responses to their needs. For example, I have shown that researchers have tended to assume that cervical cytology is a sensitive subject for South Asian women due to cultural constraints and this has deflected attention from the needs of South Asian women in their use of the service.

Finally, there is scope for more involvement of interpreters/advocates in the entire research process from formulation to data analysis. Chapter 2 showed that the interpreters/advocates not only helped with translation but added to the understandings gained in a variety of ways. This was an area where I was only able to scratch the surface. Further work on the use of advocates would provide pointers for other research projects on minority ethnic groups and

healthcare. It would increase an understanding of the dynamics of the research situation and contribute to debates about 'race' and gender difference and interviewing.

The interview data not only raise issues for further research but also areas for action. This is the subject of my last section.

6.5 Scope for action

My findings also have implications for health service delivery and point toward policy directions and ways in which policy-makers might respond to these findings to enhance South Asian women's access to healthcare. The suggestions which follow are for changes to the healthcare system and they stress that healthcare provision must be appropriate and accessible to minority ethnic service users. Many of the suggestions, however, would benefit other service users. Where appropriate, some recommendations have been included in the empirical chapters. Other recommendations are discussed below. They include general recommendations and those specific to the chosen healthcare arenas. A number of recommendations flow from the cervical cytology arena, these both link to the other healthcare arenas and are specific to screening provision.

Mainstream provision

Given the experiences of the women in this study and in the light of my review of health policy targeting minority ethnic groups outlined in chapter 1, a central recommendation is that efforts to improve South Asian women's access to healthcare must be integral to mainstream provision. The needs of South Asian women should be central to health service provision, not just added on or sidelined.

In the past, attempts to enhance access to healthcare for minority ethnic groups have centred on special provision that operates outside mainstream care. Initiatives have also focused on a number of specific diseases. This is a problem because special provision has a number of implications for the 'inclusion' and visibility of minority ethnic groups in health policy. Firstly, special provision may become a concession in the context of mainstream policy and so amount to tokenism. As McFarland *et al.* (1989) suggest, short term special needs responses do not counter long term inequalities in service delivery and do not 'include' minority ethnic groups' needs or acknowledge the multi-ethnicity of British society.

Secondly, special needs provision often marginalises provision outside mainstream budgets. There is a danger that this type of approach becomes isolated and second rate or a soft option. These negative effects are compounded in a policy climate that has seen the retraction of minority ethnic funding (Mama, 1992) and increasing competition for State handouts. Thirdly, by representing the needs of minority ethnic groups as 'special' in character people are made into 'the problem' and are seen to place extra demands on provision. This reinforces the idea that changes in policy are concessions rather than an overdue response to provide for minority ethnic groups (Pearson, 1989). Overcoming these ideas that policy changes are concessions and that minority ethnic groups are 'a problem' is a major challenge in health policy and provision. Finally, specialist provision may mean that systematic inequality or the impact of structural factors on minority ethnic groups' access to health services are not addressed head on.

Chapter 1 showed that there is a tension between treating minority ethnic groups as a problem to services because they have 'special needs' and recognising that services are a problem to minority ethnic groups (Phoenix, 1990). I would argue, with others (Madhok *et al.*, 1992), that equitable healthcare provision for minority ethnic groups requires a level of service that is comparable with that enjoyed by the majority ethnic community.

My findings suggest that healthcare provision needs to develop forms of access to healthcare that are appropriate in mainstream care, rather than separate provision which is exclusive to a client group. This would counter *ad hoc* responses to South Asian women's healthcare needs as well as the invisibility and marginalisation of South Asian women and their healthcare needs in mainstream provision. It is accepted that, in the short term, special needs approaches have gone some way toward highlighting the healthcare needs of minority ethnic groups and securing resources to this end. However, this study has shown that the healthcare experiences and needs of South Asian women are more diverse than much of the literature acknowledges, and therefore, their needs could not all be met by special provision. I feel that in the long term, special provision could mean that the needs of South Asian women are ignored or marginalised, that South Asian women continue to 'get by' and that health services are thereby absolved of their responsibility to meet the needs of minority ethnic groups.

Appropriate and effective healthcare provision does not necessarily require radical changes in healthcare provision. My findings suggest that small scale changes can bring large

improvements in the healthcare experiences of South Asian women. I would argue that effective service responses should relate to the general delivery of services not to special needs. Further, mainstream service provision must be flexible enough to meet all people's needs and healthcare needs have to be provided for in different ways, appropriate to individual need. According to Johnson (1992) the recognition of diversity may result in more generalised improvements in access where minority ethnic groups' needs may be shared with the majority ethnic population.

A key area for action is to challenge insensitivity to the healthcare needs of South Asian women as a result of the attributes of health services. Many of the accounts have suggested that the health system makes few concessions and expects users to move towards it, rather than it to move towards them. The interview data have suggested that access is constrained because the health system is insensitive to South Asian women's needs in three main areas. Firstly, due to constraints on communication with health professionals, secondly, due to the manner of delivery of health services and thirdly, because the system does not move to challenge the structural constraints that have been shown to affect South Asian women's access to healthcare. The data have also shown that this insensitivity in healthcare provision is countered by women's own ideas about healthcare, their healthcare practices in their broadest sense, their ideas about the management of health and ill health and by their desire to secure information about health, healthcare and treatment. This raises the issue of communication between healthcare providers and users in its broadest sense.

Improvements in broad communication issues

Chapters 4 and 5 have highlighted the broad aspects of communication with health professionals and shown that poor communication acts to constrain South Asian women's access to healthcare. These findings have a number of implications for policy and provision. Firstly, they make a case for more time and attention to be given to the needs of the individual and for health professionals to listen to, rather than assume, the health behaviours of South Asian women. Secondly, they make a case for communication training to be available to service providers. The approachability of health professionals has been highlighted as a constraint on access to healthcare, this has been shown for example in relation to using health services for mental health concerns. Thirdly, the findings also suggest that provision must enable women to speak the language of services. This would help women to access services with which they are not familiar, and for those with language

problems or those new to the UK, it would help them to access health services without help from others. Information about services, aspects of care and rights in service provision, including information about where services are, how they work and who to approach, should be up to date and offered in an appropriate form. Fourthly, interviews with some women have also suggested that the dissemination of information about health services and health more generally needs to be improved and that outlets including local shops and the voluntary sector should be used.

Finally, as in other studies, the interview data have shown that language assistance is an important unmet need for some South Asian women. These findings lead to the following recommendations. There is room for improvement in South Asian women's and health professionals' knowledge about Lothian Interpreting and Translation Service. No one volunteered that they had used or been offered this facility in their interactions with the GP service or with cervical cytology services. Following my discussion in chapter 4, the provision of easily available advocates who have access to resources and who are trained in health services and knowledgeable about their operation would go some way toward tackling the immediate problems of those with little or no English or those not confident in their use of English inside health services. It would also decrease women's dependence on family members, especially children, which has been highlighted as a worry for some women when using health services. In addition, the provision of advocates would provide front-line rather than anecdotal information to evaluate services and to assist the improvement of healthcare provision for minority ethnic women. The evidence suggests that advocates would be important not only in the uptake of care but would assist in South Asian women's negotiation of healthcare and health services by improving communication inside health services in its broadest sense.

Improvements in the manner of delivery of health services

Improvements in communication issues are related to the need to improve the manner in which health services are delivered to women. Chapter 4 showed that communication between some South Asian women and health professionals may be impaired if women are not informed about their healthcare options and do not have reasonable choice within health services. Access to health services may be improved by ensuring reasonable choice. For example, chapter 5 noted a lack of knowledge about cervical cytology provision outside the GP arena. Increased knowledge about availability of screening in Family Planning Clinics,

for example, might assist women to make health service choices, ensure the availability of female staff to take tests and improve communication when attending for screening.

The interview data have also shown that South Asian women's access to healthcare is limited by the sketchiness of advice and information they receive about services and treatment. The findings suggest that a number of improvements in the manner of delivery of services could be made. There is room for improvement in the role of the GP as a gateway to other forms of healthcare and services, and for GPs to be informed about what is available to relay to women. For example, chapter 3 identified a demand for information about the availability of counselling facilities. It highlighted the need for a local strategy to manage the high levels of ongoing mental health concerns. This should be at an inter-agency level. The strategy needs to encourage the use of different sources of support and advice and to increase the awareness of such services, not only among South Asian women, but among health professionals. The findings suggest that the GP has a role to play in publicising contact with other sources of support for mental health concerns, and in increasing the awareness of the healthcare options that are open to women. In particular, the findings have highlighted the fact that GPs' knowledge about the facilities offered by the women's voluntary sector needs to be enhanced.

Improvements in the manner of delivery of services are not only a case of informing women about their healthcare options and giving more and more information to them. Healthcare provision also needs to 'include' South Asian women and to build on the healthcare resources which they already possess. My findings suggest that this could be done in a number of ways.

More work needs to be done to improve the health promotion opportunities of minority ethnic groups by including them in provision. This would help to demonstrate that the needs of South Asian women are integral to mainstream care. This might include targeting material at particular groups. This is also highlighted in other studies on minority ethnic groups (Bowes and Domokos, 1995c; Howlett *et al.*, 1992). In particular, chapter 3 emphasised the need for appropriate information about diet, worries, weight, asthma, diabetes and mental health concerns.

My study has also shown that health promotion opportunities are limited by a shortage of materials in South Asian languages. Some of the material I obtained to use in the interviews was out of date and so incorrect and some of the voluntary groups that I had contact with

requested that I supply them with the information I had been able to find. This shortage needs to be rectified. However, the socio-economic profiles of the women interviewed have shown that they may not always read the language they speak. This means that information needs to be provided in a variety of different modes and disseminated in various ways. This might include taped information made available through the voluntary sector.

As noted above, another recommendation is that provision must build on the healthcare resources which South Asian women already possess. Health service practice needs to encourage the active health involvement of South Asian women in their own healthcare and to build on women's patterns of healthcare that do not involve service use. This moves away from health policy targeted at minority ethnic groups which has focused on specific diseases towards policy focusing on healthcare in its broadest sense. Chapter 3 has shown that women are keen to improve and maintain their health. This is a positive base to build on in terms of health promotion. An effective way of improving access might include positive support for self-help activities in healthcare. For example, all the empirical chapters support the case for learning about health issues in informal learning environments. They have also highlighted the role of social support in enabling access to healthcare. These activities need to be encouraged to enable access to healthcare for South Asian women. Existing community based self-help networks are well placed to do this. I have emphasised the role of women's voluntary groups in providing support to harness forms of healthcare such as the GP service and cervical cytology and shown that some women welcome sessions tackling health matters. These practices need to be publicised further, supported, extended and learned from.

Possible improvements in the manner of delivery of health services that build on the healthcare resources which South Asian women already possess extend into women's interactions with health service environments themselves. It has been suggested that positive health service experiences through the active healthcare involvement of South Asian women in their use of health services are more important in spreading health education messages than other tried and tested methods such as posters and leaflets. It is therefore important for health education messages to be appropriately conveyed by health professionals if they are to enable access to healthcare. This is seen particularly in women's accounts of cervical cytology. These findings link to the other healthcare arenas.

Chapters 4 and 5 emphasised the need for women to attend actively in health services. Chapter 5 showed that women are keen to attend for screening and that many women feel they want to know more about the service. It also identified situations where women are not given the opportunity to attend actively for screening. It emphasised that provision should include not only the test but also active and effective health education messages. This means that health promotion must be enhanced at the time the service is actually used. The evidence suggests that time spent with the individual woman, in which she has the opportunity to gain accurate information in a sympathetic environment, would enhance women's screening experience. Also, women should be kept informed about what is actually happening to them and why, in this case, at the time of screening. This should include the facility to remind women about the need for screening, even if they have already been screened.

The evidence presented in my study suggests that allowing the service user into the consultation, in this case the screening process, is essential to improve access to the service. In particular, screening practice must emphasise the promotive side of screening, as a healthy behaviour, along side the preventative nature of screening. Again this requires time and attention to be given to each individual woman. Although it has been suggested that limited information and inaccurate beliefs about screening may not affect uptake, better promotion of the preventative and promotive nature of the service may make the whole procedure less confusing and less frightening for some women, decrease their fears about the prospect of the experience of the test, and encourage irregular attenders to be screened regularly and non-attenders to be screened.

Improvements in cervical cytology screening provision

A number of specific policy recommendations also arise from this targeted preventative service. This study has highlighted the need for more effective health information about screening as well as the positive role of health visitors in the women's healthcare. Given that much remains to be done in promoting the positive and wider health benefits of screening, the work of community health professionals needs to be harnessed to enable uptake and to improve the screening experiences of women. In addition, since many of the women had been screened at the six week check up after the birth of a baby, the evidence indicates that better use could be made of this time to enhance women's understanding of cervical cytology to enable them to make an active choice about this medical intervention.

Improvements in communication would also enhance access to this service. Pre-test discussion is highly important, this should be in mutual language to enable women to be in a position to choose and be informed about the test should they go through with it. The accounts have revealed the need for specific types of information at the time of screening. This includes knowledge about screening organisation, especially the availability of the service outside GP care, and about the intervention as a whole, including further treatment. There is also a need to increase women's understanding of the risk factors of cervical cancer such as the contraceptive pill, diet, fertility history and age. This especially holds true for younger women. The evidence has shown that women are more aware of the risks of cervical cancer among older women than younger women, however, as noted in chapter 5, the incidence rate of both invasive and *in situ* cervical cancer is growing in women under 35. The evidence has also suggested that there is room for improvement in women's knowledge of risk avoidance and methods of primary prevention in relation to cervical cancer. Notwithstanding the lack of absolute proof of a sexually transmitted causal agent, women need to be told that barrier methods of contraception should give some protection from cervical cancer. This recommendation has also been highlighted in other studies on majority ethnic women (McKie, 1995).

The accounts have also highlighted the need to target particular groups of people to increase their knowledge of cervical cytology and to get screening services to these groups. Such groups include older women, non-attenders and irregular attenders. If regular screening is to be ensured in line with current health policy, health staff need to be informed about the experiences and perspectives of these groups and about women's negative experiences. Further, the data on women talking about men's attitudes to the service lead me to recommend that men need to be educated about women's health issues, including cervical cytology, and that the role of men in the development of cervical cancer needs to be widely recognised. This will help to challenge men's proprietorial attitudes toward women's bodies that have been shown in other studies, and in the current study to a limited extent (McKie, 1995; Gregory and McKie, 1992). This will also help to heighten women's understanding about the preventative nature of cervical cancer and promote the wider health benefits of cervical screening.

The findings suggest that active and effective health messages at the time of screening could enable access to the service both directly and indirectly. Direct improvements would assist the individual to see screening as part of her own healthcare rather than just a procedure or

medical intervention with which to comply. Indirect improvements through the active health involvement of women when attending for screening would enhance access to cervical cytology for South Asian women more generally, through the use of social support. The latter has been shown to be an important enablement affecting access to the service.

The accounts point toward other aspects of service provision that might be reviewed. These include modifications in the environment in which screening occurs, as well as measures to change women's perceptions of this environment. In terms of modifications in the screening environment from the data it seems reasonable to suggest that health providers need to be sensitive to women's needs for comfort and to the emotional side of screening. This would make the procedure more patient-centred. In addition, I have shown that feelings of pain, fear and embarrassment may cause some women to delay or avoid screening. These feelings need to be kept to a minimum. The need for after-care has been emphasised in the data. Two women suggested a room to 'wind down' after the test, and the accounts suggest the need for counselling support to reduce the psychological and emotional aspects of screening, should women require it. Other studies on cervical cytology have shown that these aspects of care are not widely available (Posner, 1993). My study, however, suggests that such measures might help to reduce women's experience of screening as 'a procedure', and to reduce the psychosocial costs of the intervention. These costs include the passivity that may be enforced by the procedure, also negative feelings such as stress, embarrassment, fear, pain as well as reduced assurance about the future that the test may bring.

Changes in women's perception of the screening environment would also enhance the promotive aspects of the service. Chapters 4 and 5 have shown that the learned patterns of health service use affect women's access to health services and that this is informed by a perception that the role of health services in their healthcare is to cure health problems. Chapter 5 has shown that the screening environment affects access to the service. It has also shown that healthcare restructuring is increasingly taking place in a GP environment which, the findings have suggested, is perceived to play a primarily curative role in women's healthcare. Further, chapter 4 has shown that women work with the notion that it is positive to avoid going to the GP, and other studies have identified screening clinics to be places of risk (French *et al.*, 1982). In this changing environment health education needs to promote health services, including the GP, not only as sickness spaces but as health spaces which have roles in the upkeep of health. I suggest that this may help to enhance the promotive aspects of the service and thereby enable women's access to screening.

Challenging structural constraints on access to healthcare

Constraints on access to healthcare flow not only from the specific health service environments studied but also from the women's broader life experiences. The interview data have highlighted the structural context of South Asian women's lives in all three healthcare arenas. These findings also have implications for policy and provision which must recognise and challenge the structural dimensions of access to healthcare. Although problems of access to health services in this area are not easily rectified in a large and impersonal NHS, the challenge is to offer health services whilst countering the processes of exclusion on the basis of 'race' and gender difference.

On the basis of my findings in three different healthcare arenas it seems reasonable to suggest that action is needed to challenge stereotyping and discrimination in health service delivery. This entails the constant questioning of assumptions about South Asian women's needs as well as challenging negative representations of the health attitudes and behaviours of minority ethnic groups. Such representations have been shown to affect South Asian women's healthcare experiences and to render services insensitive to individual needs. They also have implications for understanding access difficulties and access issues among South Asian women. Chapter 1 has argued that stereotyping minority ethnic groups' health beliefs and actions may result in the blame for access inequalities and the onus for change being shifted onto the minority ethnic groups themselves. This lets health services and professionals 'off the hook' (Pearson, 1989: 78) and justifies inaction.

In this context, researchers and policy makers need to be informed about the realities of minority ethnic groups' lives. This involves educating health professionals out of stereotypes of the health behaviours and attitudes of South Asian women. Also measures to challenge the widely held perception that minority ethnic groups are a drain on resources, require more time, have completely different problems from the majority ethnic population and are undeserving, toward a perception that minority ethnic groups are under-served. The challenging of stereotypes also involves a change in the focus on access problems to include the attributes of health services, not just the attributes of minority ethnic groups. Underlying all this must be a recognition of the individual and his/her health needs in order to challenge stereotyped needs and health behaviours.

Chapter 1 has shown that some commentators (Ahmad, 1993b; Stubbs, 1993) argue that challenges to racism are less advanced in health services than in other arenas of public

provision, such as social work and education. The 1976 Sex Discrimination Act makes it illegal for anyone concerned with the provision of goods, services or housing to discriminate against an individual on the grounds of sex. Discrimination on the basis of 'race' difference is also illegal under section 20 of the Race Relations Act (1976) and this should provide two incentives for change. The latter makes it unlawful for anyone concerned with the provision of goods or services to the public to discriminate on racial grounds by refusing and/or deliberately omitting to provide them with goods, facilities or services of like quality. Section 71 of the act also urges local authorities to implement equal opportunities policies (Williams F., 1989) and thereby encourages the active promotion of anti-racism. It places a duty on every local authority to eliminate unlawful racial discrimination and to promote equality of opportunity and good relations between people of different racial groups. In the light of these observations and my findings I recommend that health services must show a commitment to anti-racism and anti-sexism. For example, they must recognise that racism operates in a number of subtle ways and that the practices of health professionals may be implicated in the reproduction of racism. Racism must be challenged in all its forms and in working practices and service delivery. Integral to challenging racism and sexism on the ground is a commitment to anti-racist training as well as anti-sexist training. Health professionals should therefore be informed of the health service experiences of members of minority ethnic groups. Attention must also be paid to ways of implementing and learning from anti-discrimination measures including the experience in other welfare areas which acknowledge that inequalities emanate from structural factors that affect the lives of minority ethnic groups, and that these factors in turn impact on health experience.

As noted above, one of my substantive conclusions is that access to healthcare is linked to South Asian women's daily lives. This means that health promotion policies must take into account the multiple roles that women occupy. However, support for the obligations attached to gender roles is not recognised, and remains under-researched, in social policy and in institutional resources. Another recommendation from this study to counter the exclusion of South Asian women in health services, is that practices within health services and those of health professionals, which effectively exclude women and deny them access to health service resources need to be challenged. Chapters 4 and 5 have highlighted some inflexibility in service provision. In response, services should take into account women's needs not just those of the organisation and address the logistics of provision. This might include: more flexible opening hours; the facility of multiple appointments for more than

one family member to be seen at once; measures to increase the ease of gaining follow-up treatment, including prescriptions, at the time of consultations; shorter waiting times; and the provision of facilities including play areas for children.

Chapter 3 has also identified the overlap between women's healthcare needs and opportunities for healthcare and support for gender role obligations. On a broader scale, investment is needed in childcare in order to enable women to participate in public and health service spheres and to enhance women's healthcare opportunities. This recommendation is not new and continues to be a key concern for policy. Support services, day-care services, crèches, nurseries and after-school care need to be widely available and at reasonable or no cost to enable women to use health services and to enhance their healthcare practices. The accounts show that the women's voluntary sector plays a vital role in this respect, providing childcare and assistance with women's healthcare at the same time. This type of provision needs to be encouraged and extended in terms of staffing, hours and funding.

It is accepted that not all these improvements lie solely within the power of the health service arena. This means that policy to promote women's health cannot be confined to the medical sphere. My findings support the argument that improvements in welfare provision to enable access to healthcare need to run hand in hand with the reality of most women's daily lives.

In this conclusion I have summarised the main substantive findings, methodological achievements, issues for further study and policy recommendations arising from my research. I regard the thesis and the investigations underpinning it primarily as an attempt to listen to South Asian women's voices, to provide them with an opportunity to be heard and also to provide me with a chance to listen to them. It is my view that these views represent a pool of wisdom, knowledge and experience which could prove to be an important resource for health policy and service planning. If the challenge is to offer healthcare provision whilst countering the processes of exclusion, it is my hope that this resource will not go unused.

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Appendix 1: Socio-economic Status of Interviewees

	Int. No	Age	Employment	Education	Husband Employment	Car	Housing
Sikh	02	37	Salaried Professionals: lower grade	Higher, India	Self-employed Professionals	y	owned
	06	31	In Education	Secondary, UK	Self-employed Workers: lower grade	y	council rent
	07	44	never in paid work	Secondary, UK	Semi-skilled Manual Workers in Transport, Communic. and Services	y	owned
	08	32	never in paid work	Secondary, UK	Service Workers: intermediate grade (pt)	n	owned
	09	42	Small Proprietors (pt)	Secondary, UK	Small Proprietors	y	owned
	10	38	never in paid work	Secondary, UK	Unemployed	y	owned by family
	11	30	Salaried Professionals: lower grade (pt)	Secondary, UK	Self-employed Workers: lower grade	y	owned
	12	66	never in paid work	Secondary, India	Deceased	n	owned by family
	19	23	never in paid work	Secondary, UK	Skilled Manual Workers in Manufacturing: intermediate grade	y	owned by family
Pakistani	03	33	In Education	Secondary, UK	Unmarried	y	parental home, owned
	05	30	not in paid work	Higher, Pakistan	Small Proprietors	y	owned
	13	23	not in paid work	Secondary, UK	Service Workers: higher grade	y	owned
	14	35	not in paid work	Secondary, UK	Small Proprietors	y	owned
	18	48	not in paid work	Higher, Pakistan	Unemployed	y	owned
	21	54	not in paid work	Higher, Uganda	Small Proprietors	y	owned

	Int. No	Age	Employment	Education	Husband Employment	Car	Housing
Indian	23	28	never in paid work	Secondary, Pakistan	Skilled Manual Worker in Transport, Communics. and Services	y	owned
	31	27	not in paid work	Higher, Pakistan	Service Workers: higher grade	y	owned
	34	35	Small Proprietors (pt)	Secondary, UK	Small Proprietors	y	owned
	01	39	Salaried Professional: lower grade (pt)	Secondary, India	Unemployed	y	owned
	04	51	Small Proprietors	Secondary, India	Deceased	n	owned
	15	59	not in paid work	Secondary, India	Deceased	n	owned
	16	33	Administrators and Officials: higher grade	Higher, India, UK	Service Workers: intermediate grade	y	owned
	17	33	Small Proprietors (pt)	Secondary, UK	Small Proprietors	y	owned by family
	20	33	Small Proprietors	Secondary, UK	Small Proprietors	y	owned
	22	32	Small Proprietors (pt)	Higher, India	Small Proprietors	y	owned
	28	41	Salaried Professionals: lower grade (pt)	Secondary, UK	Nonmanual Employees in Administration and Commerce	y	owned
	35	34	not in paid work	Higher, India	Industrial and Business Managers: small enterprises	y	owned
B/deshi	24	31	never in paid work	Secondary, B/desh	Service Workers: higher grade	y	owned
	25	28	never in paid work	Higher, B/desh	Small Proprietors	y	owned
	26	64	never in paid work	Never	Retired	n	private rent
	27	27	never in paid work	Primary, B/desh	Small Proprietors	y	owned

Int. No	Age	Employment	Education	Husband Employment	Car	Housing
29	22	never in paid work	Secondary, B/desh	Mangers in Services and Small Administrative Units	y	private rent
32	41	Salaried Professionals: lower grade (pt)	Higher, B/desh	Mangers in Services and Small Administrative Units	y	owned
33	37	never in paid work	Primary, B/desh	Mangers in Services and Small Administrative Units	y	owned by family
36	54	never in paid work	Secondary, B/desh	Small Proprietors	y	owned
37	26	never in paid work	Secondary, UK	Service Workers: higher grade	y	owned

Source: Goldthorpe, J.H. and Hope, K. (1974)

Key: Never in paid work = never worked.

Not in paid work = not in paid work at present, has worked before.

Marked for women only (pt)= part-time. If not marked = full-time.

Table indicates highest level of education and Country. Does not indicate duration in education or completion.

Car = Family car

Appendix 2: The interview schedule

What does the interview involve? Information for the women interviewed

1. Firstly, thank you for agreeing to talk to me - I would like to ask you some questions about your health, how you look after yourself and who you talk things over with.
2. I will ask you some general questions about your health and your thoughts on the NHS, before moving on to ask you about your experiences of the GP and then some questions about cervical smear testing.
3. If you do not want to answer any of the questions just say so and we will move on.
4. All this information will be treated with the utmost confidence and will be anonymous - it will only be seen by me and possibly my supervisors, your identity will not be revealed.
5. It makes my job much easier if I can record our conversation to be sure of what you have said - would you object if your answers were recorded?
6. I may take a few notes during the interview, do not worry it is just to clarify what you have said.
7. Do you have any questions? Shall we begin?

STARTER QUESTIONS

Who lives here?

Where were you brought up?

How long have you lived in Edinburgh, How did you come to be here..?

Where were you before?

When did you come to the UK?

SECTION 1 HEALTH ATTITUDES AND ACTIONS

As you know, although I am interested in all aspects of the lives of South Asian women, this work is mainly about health issues...

How would you describe your health?

How would you describe your health compared to other women of your age?

- why - sick/well?
- what do to keep as well as can, what does good health mean to you
- are there any sorts of things you do to keep healthy? - what about health services?
- where get ideas? Get help carrying them out?

Do you worry about your health?

- why/why not?

Do you talk to anyone about your (general) health?

- who - Asian? Age? Lives with? Voluntary Group?
- why turn to
- how often?
- what sort of help?
- how do they help you (compared to GP) Importance of help
- get enough support?

Do you talk to anyone about your health problems?

Do you talk to different kinds of people for different health problems?

Anyone else like to talk to?

What sorts of things do you do if you get ill/in ill health?

- how things help you, where get ideas, get help carrying out, how work, what do for you?

Who takes care of you when you are ill?-Apart from Health Professionals

- how do they help you? what do they do?
- how easy is it for them to help?
- is it the kind of help you want/need?

When was the last time you felt ill, what was wrong...?

- what did you do first, Next...
- is this what you normally do when you get ill? what do...

SECTION 2 HEALTH SERVICES

Now I want to go on to ask you about some specific health services...?

GP SERVICES

PATHWAYS INTO THE SYSTEM

Are you registered with a GP? How long been with..?

- who are they- age/sex/ethnic origin + language skills;
- do they work alone or in a larger practice?

Did you choose your doctor?

- If YES how?
- If NO why? What would you look for if you could? (look for, want from)

PATTERNS OF USE

Generally, Why do you decide to go to the GP?

How often go to GP?

- What kinds of things do you go to the doctor for?
- if not work - kind of things prefer not to go to the GP for?

Colds

Upset stomach

Worries

Problems at home

Tiredness

Headaches

Skin trouble

Bladder problems

What do you do instead?

(colds/upset stomach/worries/problems at home/prevention/advice information)

Can you always get to see the GP when you want to?

- practice accessible; receptionist helpful; does appointment system work
- is Surgery welcoming; is the GP generally available
- constraints on access at particular times
- Constraints for particular conditions
- past treatment that might make you reluctant to ask about certain issues

How easy is it for you to see the doctor when you want to?

EXPERIENCE

How do you find the surgery and the way it is run - Appeals, not? Good, bad things?

Do you always see the same GP...?

- is it better to see a particular GP for some things, or important see same GP all the time?

Have you ever needed to call a GP out?

- how useful, ease of obtaining, would you consider it

Have you ever needed to see a GP at night?

- how useful, ease of obtaining

Do you ever telephone your GP for medical advice?

- would you prefer this?
- how useful is it?)

Are you satisfied with the services and care that your GP provides?

- is the range of services adequate?
- is information about them available to you in the language you prefer to speak?

How would you describe the relationship that you have with your GP?

- attitude toward you?
- how treated- Is GP generally sympathetic
- listen to you? Give enough time to discuss your problems?
- do they understand your problems?
- do you feel able to ask questions?
- what about the way you are examined..?

Do they give you enough information about your health problems and about the medication they prescribe?

Are prescriptions necessary?

In your experience what makes a 'Good' GP and what makes a 'Bad' GP?

- most/least important in a GP?

How useful is the help and advice offered by your GP?

- more or less than provided by family and friends?

Do you always do as the GP says..?

Thinking about the Last Time you went to the doctor to ask about your own health...

- when was that?
- what was wrong?
- was going to the doctor the only possible solution?
- how did the consultation go? (describe course of events)
- would you go back to the doctor if the same problems recurred (what would you do?)
- was this a typical experience?

Do GPs treat everyone the same? Where do you fit in?

- what way different + why

Some people say that GPs treat South Asians differently..?

- why people say that? why had that experience?

Does your GP provide as good a service to women as to men?

**General prompts: Affect the way that you use your GP?
 How make you feel?**

CERVICAL CYTOLOGY

Next I'd like to talk to you about preventative services available through the NHS. One of the most common is Cervical smear testing...

Do you know what a cervical smear test is?

Have you ever had one?

What do you think about women having cervical smear tests? (Importance to you)

PATHWAYS INTO THE SYSTEM

How come to have first test?

- age?
- circumstances

Have them regularly?

(springboard ask about Others- **First**- prompts, expectations)

- If **NOT** - why not? Accessibility - Appt system, welcoming environment, staff available
- Previous tests- makes reluctant, why had bad experience)
- If **NEVER** (Why? Ever asked? Consider going? Expectations? Preferences - who, where?
- talked to anyone? Husband attitude - effects?

How did you first find out about smear testing?

Do you worry at all about getting a smear test done?

- why?
- who talk to about concerns

Do you worry at all about the results of your smear test?

- why Who talk to?

Did you talk to anyone about smear testing?

- who? age? why them?
- how help you?
- more than health professionals
- importance of support - is it help want/need
- how easy is it for them to help)

Why **NOT** turn to **Other**?

Anyone like to talk to but haven't?

HUSBAND attitude?

Thinking about your last (most recent) cervical smear test...

EXPERIENCE

What prompted you to have it? - things helped to have?

- so, did you have smear when want to have it done?)

Where did you go - Is this where you usually go?

- advantages/disadvantages

Was it easy to get to?

Did you go on your own/How did people help you?

Who did the test - Is this who usually does it?

- advantages/disadvantages

What did you feel about the experience?

How satisfied were you with your last cervical smear test

- were you treated courteously, Given enough time
- did you get enough verbal and written Information about what was happening?
- did you have the opportunity to ask questions - before, during, after the examination?

How did you feel Afterwards?

- relieved, annoyed, ashamed, fine

Did you get a Result?

- when and how obtained?
- did you know what the results meant?

SATISFACTION

Could anything have been done to Improve your experience?

Gold Standard Test -What would you think about a pre test chat about your state of health, periods, method of contraception, what the test is for?

Do you feel happy about going back for another smear

- will you go back to the same place/person or elsewhere?

Do you think you were treated the same as other women using the same service?

Some people say that Asian Women do not go for smear testing, What do you think?

How improve situation?

- are women encouraged to have tests?
- do men encourage?

IF ABNORMAL SMEAR

What would an abnormal result mean (causes, treatment)

- can you tell me about your experience...?
- did you know what the result meant? What about treatment?
- who explained it (how, when, where)
- how did you feel about it?
- talk to anyone about this?
- who helped you most?

You said that you had X smears, are there any general points that you would like to talk about-good and bad sides?

- effect you going?
- how make feel?
- talk to anyone

KNOWLEDGE [if missed in interview]

- 1. What is a smear test for?**
- 2. Who needs to have a smear - which women?**
- 3. How often should have?**
- 4. Where can you go for a smear?**
- 5. Who takes smears?**
- 6. How get results?**
- 7. What doe a normal result mean?**
- 8. What does an abnormal result mean - what causes? can it be prevented? can it be treated?**
- 9. Tell me about cervical cancer - who at risk? what causes? can it be prevented? can it be treated?**

SOCIAL CONSTRAINTS

I would like to find out a little more about you...

Tell me about living in Edinburgh..?

Some people say that Asian people are treated differently in Scottish society, Has this been your experience/why do people say that?

- compared to other Asian groups?
- how make you feel?
- how effect you?)

Some people say that women are treated differently than men in Scotland - why do people say that?

- do you feel different to other women?

Do you think of yourself primarily as Asian or British or Scottish or as something else?

To round off your ideas about health as at some point nearly all of us have to make use of the NHS...

Do you think there is equal access to (various parts of) the NHS for everyone...?

- easier for other women to make use of...
- differences in own situation compared to other women...

Some people say that Asians are treated differently to Whites by the NHS, Has this been your experience - Why do you think they say that?

- why happen?
- what can be done?
- Asian women different to Asian men?

Some people say that women are treated differently to men by the NHS, Has this been your experience - Why think they say that?

How has this affected the way you use/views of the Health Service?

Is there anything I have missed out

Do you want to add anything about

- being in Scotland
- your health
- your healthcare
- the NHS
- Health Services - GPs and Smears

PROFORMA WITH KEY DETAILS

NO OF INTERVIEW

DATE
TIME

PLACE OF INTERVIEW

RESPONDENT

DATE OF BIRTH/AGE

PLACE OF BIRTH

PARENTS BP

CITY/LG TN/VILL

AGE OF ARRIVAL IN BRITISH ISLES

AGE OF ARRIVAL IN EDINBURGH

BEFORE? WHEN WAS THAT?

BEFORE?

ATTEND VOLUNTARY GROUP?

HOW OFTEN?

AGE AT MARRIAGE

LANGUAGES SPOKEN +/-OR WRITTEN

ETHNIC GROUP

RELIGION

EDUCATION

WHERE?

LEAVING AGE?

15/16 18 18FE

HIGHEST QUALIFICATION

EMPLOYMENT

PAID WORK HOW MANY HOURS

IF NO - LAST JOB/EVER HAD REGULAR JOB

HOURS

PARTNERS JOB

HOURS

IF RELEVANT WITH EMPLOYEES, NUMBER?

HOUSING

OWNED

OWNED BY FAMILY

PRIVATE RENT

COUNCIL RENT

OTHER e.g. Housing Assoc.

CAR

Do you drive it?

PHONE

ownbusiness

HOUSEHOLD MEMBERS

Who do you live with? (indicate children not at home)

ADULTS

CHILDREN

1234121234

REL TO R

AGE

SEX

COUNTRY OF BIRTH

GP

Kind of practice - single/group

Number of GPs?

Nearest to you - Easy to get there? How?

Make Appointment/Open system?

Length of Time to wait for non-urgent Appointment?

Best Time to see GP?

How many times seen GP in last 12 months?

SMEARS

Number of Smears?

Age at First Test? where? who took?

When was your Last test? where? who took?

How long have to wait for your results?

KNOWLEDGE

What for?

Who needs to have?

How often should have?

Where can go for?

Who takes smears?

How get Results?

What does a Normal result mean?

What Abnormal result mean - what causes? Can it be prevented? Be treated?

Cervical cancer - Who at risk? What causes? Can be prevented? Be treated?

Appendix 3: Category list used to analyse interview data using Hypersoft

HEALTHCARE ARENA: ACCESS TO HEALTHCARE OUTSIDE SERVICES

CATEGORY	TO BE INCLUDED IN CATEGORY
DESCRIBE HEALTH	<u>ASSESSMENTS OF HEALTH</u> Self assessments of health are a core category Incl. q.s how would you describe you health? and Compared to women of same age?
WORRY HEALTH	Incl. q. Do you worry about your health? Incl. all info. on worries about health; The importance of being healthy- why need to be healthy e.g. this incl. worries about effects of own health on others
HOW H I	<u>HEALTH BEHAVIOURS AND ACTIONS</u> How women deal with/maintain health Incl. all do to deal with/maintain health; strategies of health maintenance Incl. q. why are you so well? Incl. q. What do you do when you get ill?
LEARN HEALTH	Incl. prompt where have you learnt all these health ideas?
REMEDIES	Home remedies - informal ways of keeping healthy
CONSTRAINTS HEALTH	Incl. all problems in maintaining health e.g. isolation, racism, loneliness, problems with harnessing informal sphere - guilt at asking, all too busy - gender roles, time
RACE H	Incl. effects of ideas about 'race' difference on health and healthcare
GENDER H	Incl. the effects of ideas about gender difference on health and healthcare
GEOG H	Incl. Effects of physical distance and uptake on access
INFORMAL GENERAL	Catch all category for informal health ideas
INFORMAL H I	Non-professional help given and received. Incl. q. get help carrying out these ideas of health maintenance? Include. q. Do you talk to anyone about your general health [who, how do they help you - i.e. informal talk the function and enablements of informal care] e.g. reinforce own health ideas, influence women's decisions to interact with formal healthcare [further ideas about interaction formal and informal healthcare from informal compare] Incl. q. Do you talk to anyone about your health problems? [who and role- why turn to, how often, sort of help]
INFORMAL NEEDS	Incl. q. Is there anyone else you would like to talk to about you health? What do women need from informal sphere/social support
NEEDS HEALTH	Incl. all comments of help the women need in health actions and maintenance and in ill health
INFORMAL COMPARE	Incl. comparison of formal and informal systems of care - how influence, interact and effect each other Incl. comments about the Health Visitor
LAST ILL	Incl. q. Can you tell me about the last time you felt ill what did you do?
PREGNANCY	Women's discussions of pregnancy and maternity care

HEALTHCARE ARENA: ACCESS TO THE GP

REGISTER	Incl. ideas and pathway of registering with a GP. How come to be with that GP and why? NB. Put what would you look for if you could in GOODBADGP category
DECIDEGO	Incl. q. and ideas of how women decide to go to the GP. The "Assessing tactics" of the situation and how the situation is managed e.g. women have said they decide to go to the GP not only for themselves but for others (and their peace of mind), other factors come into play such as deference - the women don't go and put e.g. their children first. Incl. how often go to GP? How the GP is used- e.g. what access choices do the women perceive that they have?
LIST C U W H A T H S B J	Incl. the list of common complaints and how women use the GP and what they do instead colds/upset stomach/worries/problems at home/advice+info/tiredness/headaches/skintrouble/bladderproblems/painful joints
CALL	Incl. q. and experiences of and attitude to calling the GP to home
PHONE	Incl. q. and experiences of phoning the GP, in what circumstances etc., any reservations that the women may have
SURGERY	Incl. comments and concerns about surgery and the way it is run - appointments, conditions, good and bad things Incl. comments and concerns about the services offered, and the adequacy of the range of services offered
CHCON GP	Incl. ideas about choice and continuity in consulting the GP. NB. This may occur or be of more importance in certain circumstances - i.e. for particular health concerns and examination of body areas. Incl. negotiation of service environments and strategies to cope with lack of choice and continuity
CONSTRAINTS GENERALGP	Catch all category of constraints on seeing GP and accessing GP Incl. worries about going to see the GP e.g. Women talk about the need to be able to talk to the GP deeply about deep things.
RACE GP	Incl. all comments where ideas about 'race' difference is a factor influencing GP access and experience. (Race dimensions of access) NB. Incl. actual experiences not answers to direct questioning to be included in RACE GPTREAT
GENDER GP	Incl. all experiences where ideas about gender difference is a factor influencing GP experience Incl. q. easier for other women than yourself to use the GP? (gender dimensions of access)
GEOG GP	Physical enablements and constraints with access. May interact with gender.
COMMUNICATIONGP	All ideas about communication with GPs. Incl. not being taken seriously and not listening to women i.e. communication issue beyond language impacting on access to GP

INFORMAL GP	Incl. all enablements and constraints on GP access from the informal sphere. Incl. using it as a strategy and response to pre conceived constraints on using the GP Themes include the support provided by networks of women; practical help to harness services; help with communication; registering with GP
LASTTIMEGP	Incl. q. Tell me about the last time went to the GP - what for, how consultation went etc.
RELATIONSHIPGP	incl. q. Tell me about the relationship that you have with your GP? Women revealed one liners about GPs in general e.g. doctors are doctors, they are all the same
GOODBADGP	Incl. What makes a good GP and what makes a bad GP? What women need from a GP. Incl. prompt what would you look for if you could -i.e. preferences of women in choice?
NEGOTIATIONIN	Negotiation of care inside the GP consultation E.g. some women mentioned having to force the GP to give a response or care - in particular medication and this affected subsequent GP access; see male GP for some things female for others choice + continuity
NEGOTIATIONOUT	Issues of compliance with GP care, advice and medicine outside the GP arena
DRUGS	All ideas about prescriptions. Worries about using prescribed medicines and getting prescriptions
INFORMATIONGP	Incl. q. are you given enough information about your health problem? Incl. Usefulness of help and advice
REFERRALSGP	Ideas about and experiences of referrals
GPACCESS GENERAL	Catch all category about ideas of access to GP
RACE GPTREAT	Ideas about 'race' difference and access to the GP when asked straight out. NB. Put experiences in Race GP. Incl. Q. Some people say that GPs treat Asians differently what do you think? Why do people say that? Do GPs treat everyone the same? Incl. q. some people say that Asian women use the GP too much (Race dimensions of access)
GENDER GPTREAT	Ideas about gender difference and access to the GP when asked straight out. Some people say that GPs treat women differently? (Gender dimensions of access)
HEALTHCARE ARENA: ACCESS TO CERVICAL CYTOLOGY	
ATTITUDESMEAR	Incl. q. What do you think about women having cervical smear tests? All responses about attitude to testing and health checks in general; and the importance of testing to the individual
KNOWLEDGE ISFOR	Incl. What is the cervical smear test for?
WORRY SMEAR	Incl. q. and quotes Do you worry about getting a cervical smear test done? - incl. Factors that worry women except results
WORRY RESULTS	Incl. q. Do you worry about getting the results of your cervical smear test?

LEARNSMEAR	Incl. q. Where did you first find out about testing? + and responses about subsequent learning
	Incl. what tell women, how tell them and how tell, effects on decision to use
CONSTRAINTS SMEAR	Catch all category constraint on access to cervical smear testing
INFORMALSMEAR GENERAL	Incl. q. Do you talk to anyone about cervical smear testing? [who + how help] - enablements and constraints on access/service use. Incl. importance of that help/support to women Incl. compared to health professionals
INFORMAL MALE	Incl. all quotes on male attitude to cervical smear testing Incl. q. Do you talk to your husband about cervical smear testing?
<u>FIRST CERVICAL SMEAR</u>	
HOW FIRST	Incl. where, when, age etc.- prompts to have, pathway to go
EXPERIENCE FIRST	Incl. ideas about experience and expectations of first test Incl. getting result Incl. How feel after?
INFORMAL FIRST	Incl. all effects of informal care on access. Subsequent others effects on first
EXPERIENCE OTHERSMEARS	Other information about smears other than first or last
<u>LAST CERVICAL SMEAR</u>	
HOW LAST	Incl. pathway to service use and circumstances of going for last smear. Incl. where, when, who did it, age etc.- prompts to have
NB. Incl. All had only one smear	
EXPERIENCE LAST	Incl. the experience of the last test Incl. ideas of pain; body invasion Incl. ideas about experience and expectations of last test Incl. getting result Incl. How feel after? Incl. q. How did you feel after the last smear?
	Incl. prompt Do you feel happy about going back for another smear? Where will you go?
INFO LAST	Incl. q. did you have the opportunity to ask questions?; Did you get enough verbal and written information?
	Incl. info. needs - numerous - what the women want to know; circumstances of asking questions
INFORMAL LAST	Incl. ideas of how informal care enabled and disabled access to testing Incl. prompt Did you go on your own, how did people help you?
CHCONSMEAROICE	Incl. all comments that the women make about continuity and choice in going for tests. Use prompt Is that where you usually go? Incl. preferences of the women e.g. female doctors, known staff
RESULTS LAST	Incl. All information as to how the women got the results of tests
IMPROVEMENTS GENERAL	Incl. what the women wanted to know about smear testing; incl. ideas about the tension between knowing too much and knowing too little. Incl. views on service provision
	Improvements in general about testing. Incl. prompt how would you improve the situation for Asian women
RACE SMEAR	Incl. All ideas about 'race' difference on access to testing (race dimensions of access)
RACE SMEARTREAT	Incl. All ideas when asked directly about 'race' difference and access

GENDER SMEAR	Effects of ideas about gender difference on access. (gender dimensions of access)
GEOG SMEAR	Physical dimensions of access
RACE ASIAN	Incl. Some people say Asian women don't go for testing, why do you think they say that?
INFORMAL COMMUNITY	Incl. all the perceived community views about testing? Some people say that Asian women don't go, does the community encourage women to go for testing?
KNOWLEDGE WHONEED	Incl. proforma question who needs to have cervical smear tests?
KNOWLEDGE OFTEN	Incl. proforma question how often do you need to have a cervical smear test
KNOWLEDGE WHERE	Incl. q. Where can you go for a cervical smear test?
KNOWLEDGE WHO	Who takes cervical smear tests?
KNOWLEDGE NORMAL	What does a normal result mean?
KNOWLEDGE ABNORMAL	What does an abnormal result mean? Causes? Treatment? And experience if had one?
KNOWLEDGE CERVICAL	Incl. Have you heard of cervical cancer? Causes? Treatment? Who is a risk? Can it be prevented? Can it be treated?

SOCIAL CONSTRAINTS AND ENABLEMENTS

NB Social constraints asked directly

RACE SCOTLAND	Incl. All ideas about 'race' difference outside healthcare arenas. Incl. all the references to ideas about 'race' difference in England Incl. Is it different for Asian women prompt
GENDER SCOTLAND	Incl. q. Some people say that women are treated differently in Scotland? Incl. Is it different for Asian women prompt
IDENTITY	Incl. q. How would you describe yourself... as Scottish..?
ACCESS HS	Incl. q. do you think there is equal access to the health service for everyone?
RACE HS	Incl. All responses on 'race' difference and access to health services generally Incl. Q. Some people say that Asians are treated differently in the NHS? feelings and experiences in healthcare spaces Incl. answers to the prompt Do you think unequal treatment is an issue in the health service?
GENDER HS	Incl. all responses on gender difference and access to health services generally Some people say that women are treated differently in the NHS what do you think? Why would people say that

Key: Incl. = Include, q. = question, Info. = information

Appendix 4: Patterns of cervical cancer

An examination of both incidence and mortality rates of cervical cancer helps us to understand the pattern of this disease and to consider the importance of access to cervical cytology for all women. World-wide cervical cancer is the most common in women accounting for 15% of all cases (West Midlands RHA, 1995). Cervical cancer is the eighth commonest cancer in women in the UK and the commonest cancer among women under 35 (Austoker, 1994; CRC, 1994). Studies show that mortality rates from cervical cancer in the UK are among the highest in Europe (Esteve *et al.*, 1993). In the UK in 1992 1860 women died from cervical cancer giving a death rate of 63 per million women (CRC, 1994). Those who die of cervical cancer tend to do so at a younger age than many other cancers, often in middle age. This means that the loss of life expectancy is high averaging around 15 years (West Midlands RHA, 1995).

Mortality rates from the disease remain constant, implying that screening appears to have little influence on mortality (Murphy, Campbell and Goldblatt, 1987), however, the incidence of cervical cancer is increasing (Austoker, 1994; Chamberlain, 1984) and it is widely believed that the increase in mortality might have been much greater if screening were unavailable (Austoker, 1994). Epidemiological evidence indicates that screening is identifying potential abnormalities, and in combination with treatment, is prolonging survival (Austoker, 1994).

Types of cervical cancer

Cervical cancer is divided into two types, carcinoma *in situ* which is asymptomatic (i.e. without symptoms) and can only be detected by screening and *invasive* carcinoma, which is made up of symptomatic and screen detected cases. The progression of the disease is not known but it is generally accepted that invasive carcinoma is preceded by pre-malignant lesions known as cervical Intra-epithelial Neoplasia (CIN). This involves new abnormal growth in the surface layer of the cervix and is graded according to the degree of abnormality CIN I (mild), CIN II (moderate) and CIN III (severe). Studies show that although there has been no overall reduction in the incidence of invasive cervical cancer (Chamberlain, 1984), recently a small reduction in mortality may be becoming apparent (Austoker, 1994).

Women at risk from cervical cancer

Studies have focused on categories of women at risk from cervical cancer and centre on age and class differentials (e.g. Eardley *et al.*, 1985). And as noted in section 5.2.2, ethnic background may also be important in the epidemiology of cervical cancer. An examination of social class differentials shows that women in social classes IV and V attend less often and are more likely to die from carcinoma of the cervix than women in social classes I and II (Evans *et al.*, 1989). An examination of age differentials shows that mortality has risen for women aged 25-34 (CRC, 1994) and that incidence of the disease increases with age (Eardley *et al.*, 1985).

The prevalence rate of cervical cancer is also increasing for those under the age of 35. Only 15.5% of cervical cancer cases occur in women under 35, but as noted above, it is the commonest cancer in this age group, accounting for 25% of all cancers (Austoker, 1994; CRC, 1994). Between 1960 and 1980 the incidence of cervical cancer among this age group increased by 200%, while the mortality rate increased by 72% (ICRF, 1995). Since the early

1970s the rates of cervical cancer *in situ* and of invasive cancer, have increased significantly for women under 45, especially those between the ages of 25 to 34 (CRC, 1994; Scottish Cancer Registration, 1983). The majority of *in situ* cases are registered in women below 45. In contrast, invasive carcinoma is more evenly spread across the age range.

For women over 45 mortality from cervical cancer has fallen noticeably. This signifies that the rise in deaths for women aged 40-44 identified in the late 1970s and 1980s has been reversed (Austoker, 1994). However, the general trend remains that death rates increase with age. Ninety five percent of all deaths occur in women over 35 years (CRC, 1994).

Appendix 5: Costs and benefits of cervical cytology screening

Appendix 4 showed that screening has a possible preventative effect and is helpful in tackling some aspects of the problem of cervical cancer. Below I outline some arguments for and against cervical cytology. These arguments focus on the wider health benefits and disadvantages of screening, the contribution of screening to the reduction of cervical cancer and the financial cost of screening.

Benefits of screening

The dominant view is that cervical cytology has a number of benefits for women. As I have shown in appendix 4, cervical screening provision helps to prevent cervical cancer and to reduce morbidity and mortality through detection and treatment. It also helps to encourage women in the active management of their health. The service is promotive, enhancing health behaviours as well as preventative, helping women to keep healthy. Screening provision signifies a move from the medical/sickness approach to service provision, to provision that integrates the promotion of good health and healthy lifestyles with preventative medicine. Preventative medicine urges women to practice healthy behaviours, including the use of health services, to keep healthy, to take responsibility for their own health and accept information on health damaging behaviour (Holland and Stewart, 1990).

Health professionals have paid particular attention to the 'failure' of women to attend for screening (Foster, 1995; Pearson and Spencer, 1989; Eardley *et al.*, 1985). As noted in chapter 5, explanation for access differences has centred on the attributes of the women rather than on the attributes of the health services. Whatever her experience of the service if a woman does not participate she forgoes the wider health benefits described above, is labelled a non-complier and is considered to be 'irresponsible' in terms of her own health.

If participation in screening programmes is to be considered part of 'good health behaviour', this entails a number of changes from conventional patterns of health service use. Firstly, attending for screening requires those who presume themselves to be healthy to interact with health services at intervals and within age limits determined by health professionals and policy. The service 'is seeking to find potential patients to offer help rather than patients coming with problems for which they are seeking help' in a population-wide programme (Posner, 1993: 55). Secondly, use of the service entails a change in women's perceptions of the role of health services in their healthcare from being used in ill health to being used in health.

Disadvantages of screening

The minority view is that cervical screening is inherently ineffective (Foster, 1995). This challenges the dominant view that cervical screening is potentially a highly effective form of cancer prevention. Commentators have debated the contribution of cervical cytology to the reduction of cervical cancer, the wider benefits of screening, the harm-benefit balance posed by such medical interventions and problems in the organisation and management of the service.

The limited success of the cervical cytology programme has been widely discussed (Chamberlain, 1984). On the service side, it is generally agreed that the problems are rooted in organisation, accountability and commitment rather than lack of money or skill (Austoker, 1994). On the user side, screening in the UK has been largely ineffective for a number of

reasons (Austoker, 1994; CRC, 1994; Elwood *et al.*, 1984; Anon, 1985). McCormick (1989) shows that the population coverage needed for minimum detection of the disease has rarely been achieved. In addition, inequalities in uptake persist. McCormick (1989) and Eardley *et al.* (1985) show that women most at risk are still underrepresented among users, including older women and those in lower socio-economic groups, i.e. those who are most at risk from invasive cervical cancer, and those in inner city areas.

In terms of wider health benefits, Skrabanek (1990a, 1988) and Marteau (1990) emphasise the uncertainty of benefit and the extent of harm that may be associated with screening if it is undertaken with little knowledge of its purpose, accuracy and implications. One of Skrabanek's (1990a, 1988) strongest concerns is that screening is offered under false premises, that women are not 'fully' informed about the risks and benefits (Skrabanek, 1990a: 189), and that no effort is made by health services to ensure reasonable expectations of what the service can offer women:

'screening healthy people without informing them of the magnitude of inherent risks of screening is ethically unjustifiable.' (Skrabanek, 1988: 971)

Critics also stress the unpredictability of the disease and say that experts do not know enough about the relationship between minor abnormalities of the cervix and cervical cancer to be able to claim that detecting abnormalities prevents cancer. For example, cancer may not necessarily follow an abnormal result if left untreated, further it is not known which cases necessitate treatment. Also cancer may arise without evidence of progression through pre-cancerous stages (McCormick, 1989). Therefore screening may not protect all women from the disease. Others question the accuracy of results. Posner (1993) describes the difficulty in defining abnormality and McCormick (1989) discusses the unreliability of interpretation of test results and assesses the implications for the number of false positive and false negative results.

Other critics focus on the personal impact of medical interventions and the costs imposed on those who do attend. Marteau (1990) warns of the psychological harm that may be associated with forms of screening and the knock on effect this may have in terms of physical health and service use for the individual.

McCormick (1989) argues that there are a range of risks inherent in screening and subsequent treatment. Women may experience anxiety in waiting for a result (Foster, 1995; McCormick, 1989) which could be compounded if the sample is inadequately taken or incorrectly diagnosed (McCormick, 1989). Others warn of the potentially long term psychological harm caused by false positive and false negative results (Marteau, 1990; Posner and Vessey, 1988; Campion, *et al.*, 1988). Foster (1995) emphasises the distress caused by receiving a positive result which women may feel to be a diagnosis of cancer. Other concerns relate to the physical, emotional and psychological effects associated with treatment for abnormal cells (Posner, 1993; Posner and Vessey, 1988).

Criticism also warns of the wider effects of screening on health behaviour. Screening may create a 'safety net' of reliance on health professionals to identify and solve health problems (Holland and Stewart, 1990). Screening availability may in the long term, constrain healthy behaviour, for example, if a normal result were to be overgeneralised with the effect of reinforcing an unhealthy lifestyle. In addition, the false reassurance that screening may give women may make them less active in the management of their own health. Indeed the emphasis on screening and secondary prevention has distracted attention from primary prevention in addressing possible risk factors associated with cervical cancer (Foster, 1995).

This includes ignoring the role of men and educating them in the causes of cervical cancer and including them in potential treatment for the HPV virus.

Commentators have also questioned the cost effectiveness of the screening procedure (Skrabanek, 1990b; McCormick, 1989). Some have highlighted failures in the organisation and management of the programme, and claimed that the disappointing results of the cervical screening programme can be explained by its underfunding and mismanagement (Foster, 1995). For example, Foster (1995) links the accuracy of testing to the underfunding of laboratories which process the tests and the pressure of demand to compromises in the accuracy of results. Some question the need for and cost effectiveness of follow up procedures and treatment (Foster, 1995), given that the progression of cervical cancer is not fully understood.

Foster (1995) warns of the harm which screening can do and the misuse of financial resources if screening leads to misdiagnosis, overdiagnosis and overtreatment. Overdiagnosis is of increasing importance, as the sensitivity of screening keeps the risk of false positive results high. This means that more women are found with preinvasive stages of the disease than would be expected to develop cervical cancer in their lifetime. These ideas about financial cost, however, need to be balanced against personal and family interests and the economic and social costs of caring for those with cancer.

Appendix 6: The policy context and the organisation of cervical cytology services

This following discussion examines the policy context and the organisation of cervical cytology services in the UK. The financial and political dimensions of the service provide background to women's patterns of use of the service. This discussion illustrates marked changes in the location of and emphasis on screening provision.

As noted in section 5.2.4 despite its limitations, cervical screening is a valuable part of preventative healthcare provision (McKie, 1995) and is part of a policy agenda on women's health. Organised cervical cytology programmes have existed in parts of Europe and North America for over twenty years. In the UK cervical cytology has been provided since 1964 and was endorsed nationally in the 1980s. In 1988 a call-recall system was established along with the NHS screening programme national co-ordinating network which has improved coverage.

The 'NHS Cervical Screening Programme' led to changes in provision. It aimed to bring an end to more sporadic provision, and to standardise how often screening should occur and levels of abnormality necessitating recall or treatment. Despite this, studies still show regional variations in provision or test results (CRC, 1994). In Scotland variations and piecemeal development have continued (Christie, 1993; Twaddle and Reay, 1993). This has been the subject of recent media attention and public scrutiny. In Lothian current guidelines are set to screen all women between the ages of 20-60 every three years (25-64 in England and Wales, 20-60 in Scotland as a whole). Women outside this age band can be screened on request. Additionally, current policy supports regularity rather than frequency of screening to limit incidence.

Targets have also added to changes in the context of provision. Those set out in the English Health strategy 'The Health of the Nation' (DoH, 1992) require a reduction of cancer by 25%. This strategy targeted cancers of the lung, breast, skin and cervix and pledged to reduce the incidence of invasive cervical cancer by at least 20% by the year 2000 (from 15 to 12 per 10000 population). The Scottish strategy, however, does not set targets for mortality reduction but stresses the preventable nature of the disease (Scottish Office, 1992).

These arrangements and targets mark changes in the tone and location of provision. Foster (1995) argues that in the early days of provision women had to opt in to screening, now provision is moving toward a system where few women are allowed to opt out. According to McKie (1995: 453) 'Increasingly...encouragement is becoming surveillance of numbers for the attainment of targets'. The incentives are linked to local screening provision. Health service restructuring has led to shifts in preventative healthcare away from specialist centres, into more widely available primary healthcare services and away from Health Board or community clinics. This is part of a wider emphasis in health policy on health promotion and illness prevention in General Practice.

The White paper 'Promoting Better Health' states that 'The government intends to positively encourage family doctors and primary healthcare teams to increase their contribution to the promotion of good health' (Secretaries of State for Social Services, Wales, Northern Ireland and Scotland, 1987). The GP contract (1990) set targets and introduced financial incentives linked to remuneration to encourage high levels of cervical screening. Currently general practitioners are locked into a system whereby they are

contractually required to conduct tests. Targets for uptake effect their working budgets. If over 80% of all eligible women GP users have been screened every 5.5 years then all payment is made. If between 50 and 79% coverage is achieved the GP is liable to be financially penalised and receives 33% of full payment. And if less than 50% coverage is attained then no payment is made. This has led to minority ethnic groups being blamed for the low uptake of cervical cytology in some areas (Anon, 1991).